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ABSTRACT

This report, prepared pursuant to Public Law 98-183 (Child Abuse Amendments of 1984), examines the nature and extent of the practice of withholding medical treatment or nourishment from infants born with disabilities and makes recommendations to remedy deficiencies in existing law. Evidence suggests that decisions to withhold medically indicated treatment continue to occur despite being prohibited by federal law. The report discusses the effect of the relationship between parents and physicians on decisions to withhold medically indicated treatment; examines the role of quality of life assessments and economic considerations in medical nontreatment decisions; addresses whether the Child Abuse Amendments of 1984 and Section 504 of the Rehabilitation Act of 1973 have been properly implemented and enforced; reviews state laws and Constitutional issues; reports on the incidence of discriminatory denial of medical treatment; explores whether child protective services agencies and hospital infant care review committees are fully complying with the Child Abuse Amendments; and considers whether medical discrimination against children with disabilities is part of a larger problem involving discrimination in the provision of medical treatment to persons with disabilities of whatever age. Appendices contain state-by-state evaluations of child protective services agencies; replies of affected federal agencies to the report's findings; and documents relating to legislation, regulations, and court litigation. (JDD)

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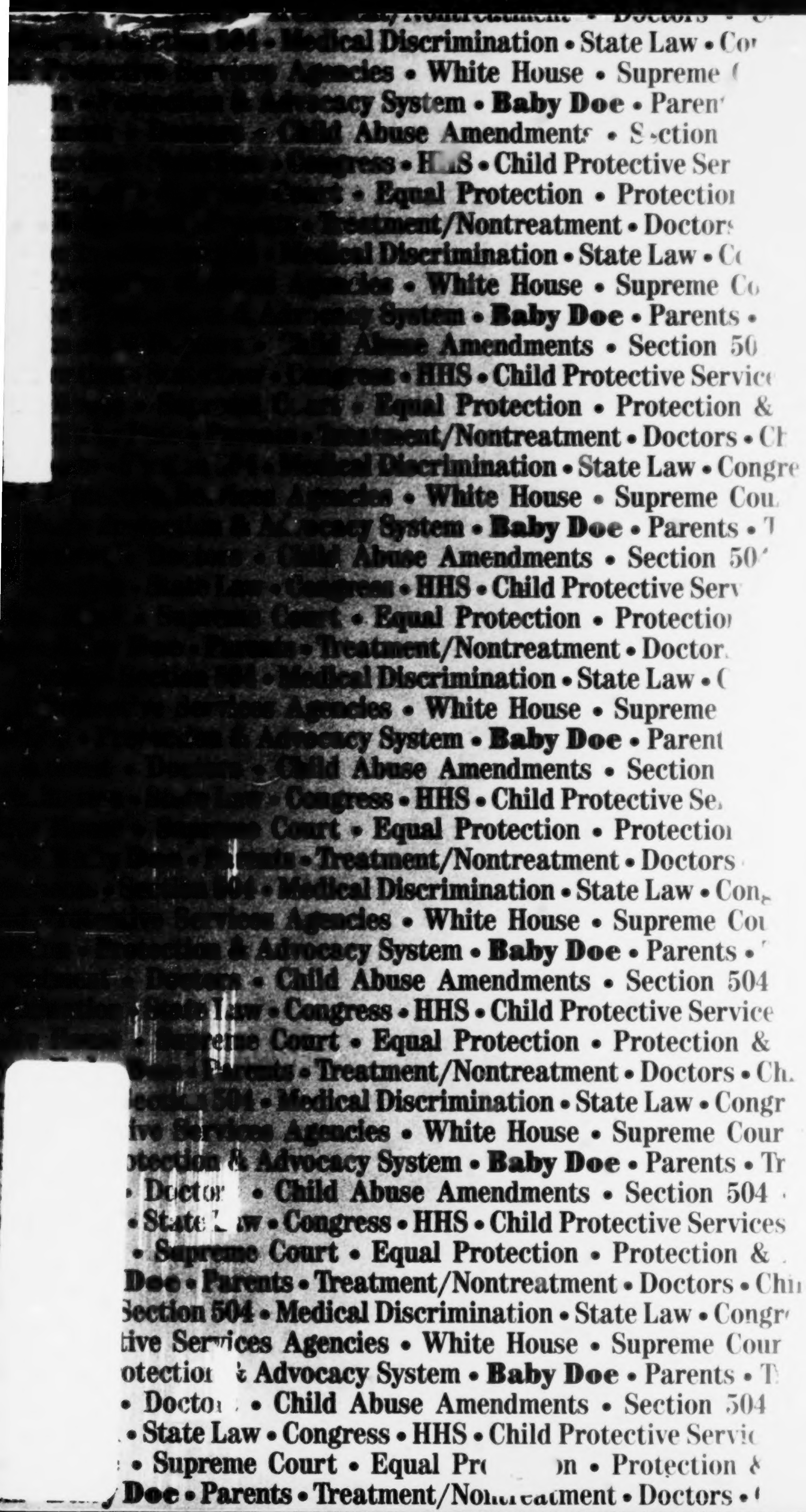

A Report of the
U.S. Commission
on Civil Rights
September 1989

Medical
Discrimination
Against
Children
with
Disabilities

U.S. COMMISSION ON CIVIL RIGHTS

The U.S. Commission on Civil Rights is an independent, bipartisan agency first established by Congress in 1957 and reestablished in 1983. It is directed to:

- Investigate complaints alleging that citizens are being deprived of their right to vote by reason of their race, color, religion, sex, age, handicap, or national origin, or by reason of fraudulent practices;
- Study and collect information concerning legal developments constituting discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, handicap, or national origin, or in the administration of justice;
- Appraise Federal laws and policies with respect to discrimination or denial of equal protection of the laws because of race color, religion, sex, age, handicap, or national origin, or in the administration of justice;
- Serve as a national clearinghouse for information in respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, handicap, or national origin;
- Submit reports, findings, and recommendations to the President and Congress.

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A Report of the
U.S. Commission
on Civil Rights
September 1989

Medical Discrimination Against Children with Disabilities

LETTER OF TRANSMITTAL

The President
The President of the Senate
The Speaker of the House of Representatives

Sirs:

The United States Commission on Civil Rights transmits this report to you pursuant to Public Law 98-183.

Medical Discrimination Against Children with Disabilities examines the nature and extent of the practice of withholding medical treatment or nourishment from infants born with disabilities and makes recommendations to remedy deficiencies in existing law. The report is based on two Commission hearings and substantial staff research aided by experts and consultants.

Available evidence suggests that decisions to withhold medically indicated treatment from infants born with disabilities continue to occur despite being prohibited by the Child Abuse Amendments of 1984. Discussed in the report is the effect of the relationship between parents and physicians on decisions to withhold medically indicated treatment, a major issue in the Supreme Court's invalidation of Infant Doe regulations in *Bowen v. American Hospital Association.* The report also examines the role of quality of life assessments and economic considerations in medical nontreatment decisions, whether the Child Abuse Amendments of 1984 have been properly implemented and enforced, enforcement of section 504 of the Rehabilitation Act of 1973 and efforts of the Department of Health and Human Services in that regard, whether child protective services agencies and hospital infant care review committees are fully complying with the Child Abuse Amendments, and whether medical discrimination against children with disabilities is part of a larger problem involving discrimination in the provision of medical treatment to persons with disabilities, of whatever age.

The many recommendations in the report include a recommendation that the Executive branch give careful consideration to resuming investigation of allegations of medical nontreatment based on handicap, and that it initiate enforcement of section 504 of the Rehabilitation Act where allegations are found to be justified. It is our hope that the extensive information and analysis contained in the report will be of assistance to you in the formulation of public policy.

William B. Allen, *Chairman*
Murray Friedman, *Vice Chairman*
Mary Frances Berry
Esther G. Buckley
Sherwin T.S. Chan
Robert A. Destro
Francis S. Guess
Blandina C. Ramirez

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Overall supervisory responsibility for the report rested with William J. Howard, General Counsel, and Brian D. Miller, Deputy General Counsel. Preparation of the substantive content of the report was carried out primarily by Commission attorney Thomas J. Balch and Assistant General Counsel Jeffrey P. O'Connell. Also contributing to the report were Commission attorneys Vincent A. Mulloy, Susan T. Muskett, and Joseph J. Piccione.

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CONTENTS

Executive Summary 1

1. **Fundamental Rights: An Introduction to Medical Discrimination Against People with Disabilities** 18
Oklahoma Case 19
Bloomington, Indiana, Infant Doe Case 20
Commission Approach 21
A Legacy of Discrimination 23

2. **The Physician-Parent Relationship and Treatment/Nontreatment Decisionmaking** 26
Factors that Impair Independence in Parental Decisionmaking 26
Influence of Physicians 27
Misinformation Among Medical Personnel 30
Weight of Parental Decisions 30
Conclusion 31

3. **The Role of Quality of Life Assessments in Denial of Medical Treatment** . 32
Impairment or Societal Attitudes? 32
Positive Quality of Life for Persons with Disabilities 34
Quality of Life and Down Syndrome 36
Inaccurate Prognoses 39
The Limitations of Medical Experience 43
Families, Society, and Persons with Disabilities 45
Propriety of Quality of Life Judgments 46
Conclusion 47

4. **The Role of Economic Considerations in Denials of Medical Treatment** 48
Costs of Residential Placement 51
Family Placement 52
Productivity of Persons with Severe and Profound Disabilities 53
Conclusion 55

5. **State Law** 56
Increasing Societal Interest in Protecting Children 56
Different Treatment of Children with Disabilities 58

Conclusion 60

6. **The Rehabilitation Act of 1973** 61
Enactment of Section 504 of the Rehabilitation Act 61
Resort to Section 504 in the Aftermath of the Bloomington Infant Doe Case 63
The "Interim Final Rule" of March 1983 64
President's Commission Report 65
American Academy of Pediatrics v. Heckler 68
Proposed 504 Rule, July 1983 69
Final 504 Rule 70
Effect of *University Hospital* 71
Bowen v. American Hospital Association 73
Importance of Section 504 Enforcement 77
Conclusion 77

7. **The Child Abuse Amendments of 1984** 79
The Standard of Care 82
Exceptions to Providing Treatment 88
Enforcement of the Child Abuse Amendments 90
Conclusion 92

8. **Constitutional Issues** 93
The Constitutional Rights of Newborn Children with Disabilities 94
Factors Limiting the Rights of Newborn Children with Disabilities 98
Conclusion 101

9. **The Incidence of Discriminatory Denial of Medical Treatment** 103
Difficulties of Estimation 103
Disincentives to Whistle Blowing 104
Surveys of Physician Attitudes 104
Turnbull Analysis 106
Investigative Reporting 107
Testimony from People with Disabilities and Their Relatives 108
Recent Medical Literature 109
Conclusion 110

10. **Child Protective Services Agencies and Enforcement of the Child Abuse Amendments of 1984** 111
CPS Delegation of Investigative Responsibility 111
Special Relationship Among CPS Agencies and Doctors 113
CPS Agencies' Failure to Comply with Federal Regulations 115
CPS Attitudes to Treatment Principles 115
Conflict of Interest 117
Conclusion 117

11. **The Role and Performance of Infant Care Review Committees** 118
History 118
Infant Care Review Committees in Action 122
Infant Care Review Committees and Reporting 127
Limitations of Hospital Self-policing 128
Conclusion 129

12. **The Performance of the Federal Government** 130
Section 504 130
The Child Abuse Amendments of 1984 139
Conclusion 141

13. **The Protection and Advocacy System: A Resource for Enforcement** 142

14. **Findings and Recommendations** 148

A Dissenting View on the Report *Medical Discrimination Against Children with Disabilities*, by William B. Allen, Chairman 154

Statement of Commissioner Robert A. Destro 207

Appendices

A. Incidence of Congenital Anomalies 213
B. Statement of H. Rutherford Turnbull III on Incidence of Discriminatory Denial of Medical Treatment 219
C. State by State Evaluation of Child Protective Services Agencies 233
D. Verified Answers 297
E. Federal Affected Agency Replies 383
F. *In re* Infant Doe 389
G. Section 504 Final Rule 393
H. *Bowen v. American Hospital Association* 430
I. Child Abuse Amendments of 1984 459
J. Child Abuse Amendments Final Rule 468
K. *In re* Steinhaus 493

Executive Summary

Introduction

In convening the first of two hearings held by the United States Commission on Civil Rights in connection with the subject matter of this report, the Commission announced that its purpose was to "attempt to determine the nature and extent of the practice of withholding medical treatment or nourishment from handicapped infants and to examine the appropriate role for the Federal Government." Expressed otherwise, the subject of *Medical Discrimination Against Children with Disabilities* is the so-called Baby Doe issue.

The Commission's interest in the Baby Doe issue was sparked by events that began in the spring of 1982, when national attention focused on the increasingly desperate efforts of potential adoptive parents and a guardian *ad litem* in Bloomington, Indiana, to save the life of an infant boy born with a tracheoesophageal fistula, a failure of the esophagus and trachea to be properly connected. A child with this condition will starve without the necessary corrective surgery, which has better than a 90 percent chance of success.

Setting the Bloomington Infant Doe apart from most infants, however, was not so much the tracheoesophageal fistula but the presence of Down syndrome, a congenital disability that usually produces some degree of mental retardation. Even were the surgery successful, the attending obstetrician advised the parents, "this still would not be a normal child. . . .Some of these children. . .are mere blobs." Declining to authorize surgery, the parents were upheld by the State trial and appellate courts, and Infant Doe died while an appeal was being filed to the United States Supreme Court.

This and other cases of discriminatory denials of medically indicated treatment of infants with disabilities are recounted in *Medical Discrimination Against Children with Disabilities*. Though much has been said and written about the Baby Doe issue, the uniqueness of the Commission's report lies in the comprehensiveness both of the subject matter it treats and of the period of time it examines. For in addition to discussing Baby Doe incidents in this and in the last decade, separate chapters of *Medical Discrimination Against Children with Disabilities* examine:

- The relationship between physician and parents and its effect on decisions to withhold medical treatment from disabled infants. This was a major issue in the 1986 decision of the U.S. Supreme Court in *Bowen v. American Hospital Association*, invalidating the Department of Health and Human Services' Baby Doe regulations.
- The role of quality-of-life assessments in decisions to withhold medically indicated treatment from disabled infants, exemplified most notably by the quality of life formula, $QL = NE \times (H + S)$, which influenced a team of physicians at Oklahoma Children's Memorial Hospital in denying treatment to 24 out of 69 babies born with disabilities. In this formula, QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society.

- The role of economic considerations in decisions to withhold medically indicated treatment from disabled infants.
- The universal acceptance under State child neglect statutes of governmental intervention in medical treatment decisionmaking where the children at issue do not have disabilities.
- The Rehabilitation Act of 1973 and resort to section 504 of that act in the aftermath of the Bloomington Infant Doe case; the President's Commission's Report; the proposed Baby Doe regulations; and the Supreme Court's decision in *Bowen v. American Hospital Association.*
- The Child Abuse Amendments of 1984, the standard of care set forth therein, and the effectiveness of the amendments in addressing the Baby Doe issue.
- Constitutional issues.
- Child protective services agencies and their enforcement of the Child Abuse Amendments of 1984.
- The role and performance of hospital-based infant care review committees.
- The performance of the Federal Government in enforcing section 504 and the Child Abuse Amendments.
- Use of the protection and advocacy system as a means of strengthening enforcement of the Child Abuse Amendments.

Pursuant to its statutory mandate to "submit reports to the Congress and the President at such times as the Commission, the Congress or the President shall deem desirable," *Medical Discrimination Against Children with Disabilities* concludes with the Commission's findings and recommendations. These findings and recommendations are reproduced at the end of this executive summary, following a synopsis of each of the chapters upon which they are based.

The Physician-Parent Relationship and Treatment/Nontreatment Decisionmaking

Much of the debate over the question of denying treatment to children with disabilities assumes a conflict between the prerogative of parents to choose medical treatment for their children and the responsibility of government to intervene on behalf of the child where the parents decline to authorize treatment. Ignored, however, is whether, given the extent of physicians' influence on parents in the decisionmaking process, the parents' consent to withhold medical treatment is, in fact, informed consent. In practice, doctors are often the prime movers in denying the treatment.

The period surrounding the birth of an infant is one of great stress and emotion for the infant's parents. The birth of an infant with a disability typically comes to them as a great shock, with feelings of depression, anger, and guilt. Because most parents have had little or no interaction with people who have disabilities, their assessments of their infants' conditions and prognoses may have little basis, and they thus turn to the attending physicians for information and recommendations. As one commentator noted, "[P]hysicians set the agenda. The person. . .who has the ability to set the agenda has to a large degree the ability to control the outcome." Physicians with a bent toward denial of treatment for persons with disabilities can be quite insistent in conveying negative information. There appears to be near unanimity from health care personnel who support treatment in a Baby Doe situation as well as those who oppose treatment that, in all but a handful of cases, the manner and content of the medical provider's presentation of the issue will be decisive in the parental decision whether to authorize treatment.

Unfortunately, there also exists misinformation among many health care personnel and bioethicists advising parents on the advances and alternatives available to children with disabilities. As one witness at the Commission's hearings testified:

> Regrettably, reports of the advances in special education, habilitation and rehabilitation have not yet received wide dissemination in either the popular media or the literature of other professions. . . .
>
> [O]ur review of the medical literature and the literature of the new bioethicists revealed that typical physicians and bioethicists have little or no familiarity with life possibilities or community resources available to individuals who are born with handicaps.

Medical Discrimination Against Children with Disabilities focuses solely on questions of discrimination, addressing medical services provided or required to be provided, that are withheld from individuals with disabilities precisely because of their disabilities. It is neither the province nor the purpose of the Commission to oversee, evaluate, or question the exercise of legitimate medical judgment inherent in decisionmaking concerning medical treatment. A civil rights issue appropriate for examination in this report arises in the context of medical treatment decisionmaking only when such decisionmaking is influenced by factors extraneous to the science and art of medicine: when color, race, age, handicap, or national origin lead to a difference in treatment despite being irrelevant to the bona fide medical judgment.

Denial of Treatment to Newborn Children with Disabilities

The record of the Commission's inquiry leaves no doubt that newborn children have been denied food, water, and medical treatment solely because they are, or are perceived to be, disabled. The Commission concurs with the Senate Committee on Labor and Human Resources, which declared that there was a "sufficient body of evidence" indicating that infants with disabilities were being denied treatment, "not isolated to one or two instances." In some cases, the discriminatory denial of treatment was based on ignorance and false stereotypes about the "quality of life" of persons with disabilities and, in others, misconceptions about the nature of the particular disability the child would have if he or she were permitted to survive.

Attempts to quantify denials of treatment, now or in the recent past, are subject to inherent limitations. When a course of lifesaving treatment is rejected for a child with a disability, the decision typically is not reported to statisticians or public officials. Denial of treatment cases typically come to public attention when a family member or health care professional reports the case to a public agency or rights advocate. Isolated instances of treatment denials at major hospitals have been reported in medical journals in the 1970s and 1980s, written by physicians seeking open acceptance of treatment practices in the medical community. Attitudes of treating physicians and other health care personnel can help judge the prevalence of denial of treatment. Two highly significant surveys of pediatricians published in 1988 suggest that contemporary denial of treatment is not infrequent. As perceived possibility of mental retardation in an infant increased, the tendency of pediatricians to suggest surgery for unrelated medical problems decreased. These surveys supplement the underreporting of discriminatory denials of treatment. Appendix C of this report, moreover, provides evidence that underreporting of denial of treatment cases is a problem in hospital infant care review committees when all the parties in the review process are in agreement on the decision not to treat. In these cases, State child protective services agencies are not notified, contrary to the requirements of the Child Abuse Amendments of 1984.

Quality of Life Assessments

The arguments typically advanced to support denial of lifesaving medical treatment, food, and fluids based on disability are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities. A Nation committed to the equal protection of the laws should address the very real problems people with disabilities and their families face through fostering supportive services and social acceptance, and through defending the statutory rights of persons with disabilities to accessible and integrated transportation, housing, education, health care, and employment. To accept a projected negative quality of life for a child with a disability based on the difficulties society will cause the child, rather than tackling the difficulties themselves, is unacceptable. The Commission rejects the view that an acceptable answer to discrimination and prejudice is to assure the "right to die" to those against whom the discrimination and prejudice exists.

The Commission received extensive testimony documenting the possibilities that people with disabilities can have when barriers to their full integration are decreased, adequate access is established to education and employment, and pessimistic prognostications are not permitted to become self-fulfilling prophecies. Research indicates that a negative parental attitude tends to change over time, with increased interaction with the child.

Medical progress has been ongoing, making predictions based on past experience obsolete. Surgeon General C. Everett Koop, for example, testified before the Commission that: "My own lifetime has seen a complete reversal of success and failure. When I first began in the field of pediatric surgery in 1946, most of the things that now have a 95 percent survival had a 95 percent mortality, and indeed, some carried a 100 percent mortality." A substantial body of evidence shows that time and time again predictions of a poor quality of life made at birth for a child with a disability are subsequently proven wrong. Why do many negative predictions about the future quality of life made at birth for a children with disabilities turn out to be wrong? Physicians may have a propensity for negative prognosis at least in part because they tend to see children with disabilities at the time that the children are in the hospital and their conditions are at their worst. Those who have contact with people with disabilities on a more regular basis, when they are not in an immediate medical crisis—such as their teachers, coworkers, and family members—tend to have much more positive views of their abilities.

The quality of life argument extends beyond the life of the person with a disability. It is frequently argued that the continued existence of a person with disabilities will be a burden on the person's family or on society as a whole. In other words, the burden the person causes for others outweighs his or her legal and moral rights to lifesaving treatment.

There is an important difference between technical medical judgments over whether a given course of treatment is likely or not to preserve life or ameliorate an impairment and judgments about whether a person's life is worth preserving through lifesaving medical treatment. The first sort of judgment is one that is uniquely medical in nature. The second sort of judgment is not, properly speaking, a "medical" one. It is a social judgment. The second judgment no more becomes a "medical" judgment by virtue of its implementation through the denial or provision of medical treatment than the decision whether to impose capital punishment becomes a "medical" judgment if execution is by lethal injection.

Recent decades have seen significant, although mixed, progress in dealing with the burdens on people with disabilities and in recognizing their rights and full humanity. At the Federal level, section 504 of the Rehabilitation Act of 1973 applies a general principle of nondiscrimination based on handicap to all programs or activities receiving Federal financial assistance; the Education for All Handicapped Children Act of 1975 promises to all children with disabilities a "free appropriate public education which emphasizes special education and related services designed to meet their unique needs"; the Developmental Disabilities Assistance and Bill of Rights Act gives the Nation's assurance "that all persons with developmental disabilities receive the services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community"; and the Architectural Barriers Act of 1968 is intended to make public buildings physically accessible to people with disabilities.

Economic Considerations

Today, the real economic costs associated with disability are less a function of the disability or its severity than of a policy that tends to segregate and isolate, at enormous public cost, persons considered most severely disabled. The assumption has been that the severity of the disability is the major determinant of lifetime cost and, consequently, that the more severely disabled a child may appear to be at birth, the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency. This assumption is a self-fulfilling prophecy: a diagnosis of severe disability leads to placement of a person in an institutional and nonwork environment that significantly limits that person's capability and entails far more expense than necessary.

Cost-benefit analysis as a justification for denial of treatment to people with disabilities implies discrimination based on disability, because such evaluations are not typically employed in other contexts. The Commission emphatically rejects the view that lifesaving medical services should be provided or denied to any group of people based on their estimated economic worth to society.

Evidence indicates that the average annual cost of residential services varies more by the type of residential option employed than by the level of need of the client. Group homes, apartments, and family-type homes have been found significantly less costly than institutions for individuals at all levels of disability, including the most severe levels. A clear trend in the direction of family-type placements, the least costly alternative, is developing, especially for children. It seems probable that in real terms the average cost of residential placement for people with disabilities is headed downward.

Despite the cost advantage and desirability of family placement, most contemporary Federal and State policies do not encourage it. Important, often unrecognized, historical reasons are responsible for this. In the early part of this century, the eugenics movement gave rise to the establishment of institutions to remove persons with disabilities from their communities and families because they were thought to be dangerous and responsible for society's ills.

Only recently has an attempt been made to change the Federal medicaid legislation to give priority in funding to families and community homes. One attempt is the proposed Medicaid Home and Community Quality Services Act of 1987, which has yet to be enacted. Because providing support for the family is the most cost-efficient way to provide residential services, changing the economic incentives to emphasize family placement rather than institutionalization would significantly reduce the cost associated with disability.

State Law

In popular debate, the question of whether children with disabilities should be denied lifesaving treatment has frequently been couched as though the issue were whether the government should intrude into matters of parental discretion. However, the universally accepted law has been that when parents make treatment decisions that will undoubtedly lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating lifesaving medical care. Only when children have disabilities has the claim of parental autonomy been given serious sympathetic consideration.

Every State provides a statutory basis for the civil authorities to act to protect a child whose life or well-being is threatened by abuse or neglect. In the jurisdictions that receive Federal funding for child abuse and neglect programs, this law must be applied to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions in order to comply with the Child Abuse Amendments.

Parens patriae is the legal doctrine which provides that the state has the authority, in proper circumstances, to intervene in the normal parent-child relationship for the protection of the child. Although primary authority is vested in the parent, that authority is restricted, or even abrogated in full, whenever that authority is abused.

The Rehabilitation Act and Section 504

Enforcement of section 504 of the Rehabilitation Act provides certain advantages not present in the Child Abuse Amendments alone. Section 504 reaches medical discrimination against people with disabilities of any age, while the coverage of the Child Abuse Amendments is limited to children. Additionally, the Child Abuse Amendments apply only to States that choose to accept Federal funding for their child abuse programs.

It creates a strange anomaly for the Federal Government, under section 504, to mandate that State agencies enforce detailed national standards forbidding medical discrimination, while permitting Federal funds to be used for programs that are engaged in the same discrimination. The Federal Government enforces racial and sexual antidiscrimination standards for recipients of its funds; it should do the same to prevent medical discrimination against persons with disabilities.

Section 504 provides:

> No otherwise qualified handicapped individual in the United States. . .shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . .

Section 504 has been called "the first major civil rights legislation for disabled people. In contrast to earlier legislation that provides or extends benefits to disabled persons, it establishes full social participation as a civil right and represents a transformation of federal disability policy." Modeled on legislation prohibiting race and sex discrimination by recipients of Federal financial assistance, section 504 may be enforced not only by cutting off such assistance but also through suits for injunctive relief by the Attorney General and by aggrieved private individuals.

Reacting to the Infant Doe case and the widespread negative response to it, President Reagan sent a memorandum to the Attorney General and Secretary of Health and Human Services in April 1982 on the enforcement of Federal laws prohibiting discrimination against individuals with a disability. The memorandum required HHS to issue an explanation to health care providers of section 504's applicability to the denial of treatment to newborn children with a disability. HHS was also to enforce section 504 and other appropriate Federal laws to prevent the withholding of potentially lifesaving treatment from children with a disability that would normally be provided to children without a disability. In May 1982, the Office for Civil Rights of the Department of Health and Human Services sent hospitals receiving Federal financial assistance a Notice to Health Care Providers which indicated that it was unlawful to deny nutrition or medical or surgical treatment to an infant with a disability if the denial was based upon the existence of a handicap and the handicap did not render treatment or nutritional sustenance medically contraindicated. Reflecting a concern that hospitals or their staff might attempt to do indirectly what could not lawfully be done directly, the notice stated that hospital "[c]ounseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under Section 504." In December 1982, internal guidelines for investigating complaints of discriminatory denial of treatment were sent to the regional divisions of the HHS Office for Civil Rights.

Regulations under Section 504

In March 1983, HHS published an Interim Final Rule. The Supplementary Information published with the Interim Final Rule stated that the purpose of the rule was to "acquire timely information concerning violations of Section 504 that are directed against handicapped infants, and to save the life of the infant." Expressing concern that individuals with knowledge of actions violating section 504 did not have adequate opportunity to give immediate notice to governmental authorities, HHS designed the Interim Final Rule to increase public knowledge of the law, including the manner of bringing suspected violations to the attention of HHS, as well as increase the ability of HHS to investigate alleged violations promptly. In April 1983, a Federal district court judge invalidated the Interim Final Rule on procedural grounds, holding that the Interim Final Rule should have been published for public comment.

Shortly after the judicial invalidation, HHS published a proposed rule substantially similar to the Interim Final Rule. After intensive negotiations with medical organizations and disability rights advocacy groups, the Final Rule was promulgated with significant revisions and contained four mandatory provisions. The Final Rule established basic duties for State child protective services agencies receiving Federal financial assistance in dealing with reports to them of medical neglect of children with disabilities. Each such agency was obligated to establish and maintain procedures to ensure that the agency use its "full authority. . .to prevent instances of medical neglect of handicapped infants." The procedures included requirements that health care providers report instances of known or suspected medical neglect on a "timely basis"; that a method be established for the agency to receive these reports; that there be immediate review, and where appropriate, onsite investigation, of such reports, and provision for the protection of "medically neglected handicapped infants," including, if necessary, court orders to compel necessary nourishment and medical treatment. Further, each State agency was to provide timely notification to HHS of every report of "suspected unlawful medical neglect of handicapped infants."

Some medical organizations promptly challenged the new rule as unjustified by section 504. The Supreme Court struck down the mandatory provisions of the Final Rule by a 5-3 vote. Only four Justices, however, joined in the opinion, making it a nonbinding plurality, rather than a majority, opinion. The plurality opinion focused on the lack of evidence in the administrative record sufficient to support the regulation: "A hospital's withholding of treatment when no parental consent has been given cannot violate section 504, for without the consent of the parents or a surrogate decisionmaker the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap.'"

A central problem with the *Bowen* plurality opinion is its suggestion that section 504 places no constraints on a Federal financial assistance recipient's discriminatory denial of treatment to a person with a disability if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child's medical treatment. (The logic of the plurality opinion applies equally to such authorizations by other surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities.) In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient's involvement, would otherwise be prohibited discrimination. A recipient's substantial involvement in a nonrecipient's discriminatory practices should be held to violate section 504.

The Commission's hearings and research supply information related to the issue that the Court considered not to have been satisfactorily addressed in the administrative record at the time *Bowen* was decided. The Commission believes that decisions nominally made by parents to deny treatment to children with disabilities often may in fact be generated by health care personnel who act as the agents of health care facilities. In such cases, health care providers who do not provide lifesaving medical treatment to children with disabilities, which would be provided were it not for the disabilities, should be held to violate section 504 despite parental acquiescence in the treatment denial.

In light of this, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends that the Executive branch give careful consideration to resuming investigation of allegations that children with disabilities are discriminatorily denied medical treatment based on handicap and initiate enforcement of section 504 in cases in which the allegations are found to be justified.

Because there was no binding majority opinion, and because the plurality opinion is ambiguous, it might be appropriate for the Department of Health and Human Services to act to enforce section 504 in a well-documented instance of discriminatory failure to report as a way of ultimately obtaining clarification or adjustment from the Court.

Child Abuse Amendments

The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care that States which receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

Virtually all States receive funds under the Child Abuse Prevention and Treatment Act, and the Child Abuse Amendments therefore apply to them. Additionally, the District of Columbia, as well as Puerto Rico, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, and American Samoa receive such grants and are bound by provisions of the amendments.

Perhaps the best short statement of the medical standard of care established by the Child Abuse Amendments is found in the Supplemental Information HHS published with the Proposed Rule:

> [F]irst, all such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication. Second, all such disabled infants must be given medically indicated treatment. Third, there are three exceptions to the requirement that all disabled infants must receive treatment, or, stated in other terms, three circumstances in which treatment is not considered "medically indicated."

The centerpiece of the Child Abuse Amendments' standard of care is found in the phrase that treatment must be that "most likely to be effective in ameliorating or correcting all [life-threatening] conditions." It is the care that must be provided to all children covered by the law unless one of the three exceptions applies. This definition creates a high standard of care. Children covered by the law must be provided the treatment "most likely to be effective," not just the level of treatment that would be provided to their nondisabled counterparts. This places a responsibility on physicians to become knowledgeable about and employ the best available treatment rather than simply to avoid discriminating on the basis of disability.

Exceptions to Providing Treatment

The Child Abuse Amendments establish three exceptions to the requirement to provide the treatment most likely to correct or ameliorate a child's life-threatening conditions (maximal treatment)—although "appropriate nutrition, hydration, and medication" must always be provided. The exceptions are when in the treating physician's or physicians' reasonable medical judgment:

> (A) The infant is chronically and irreversibly comatose;
>
> (B) The provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or
>
> (C) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

State Programs and Authority

Under the statute as enacted, within 1 year after the act became law, State agencies desiring to receive the Federal funds had to have procedures and programs to permit coordination with the health care facilities, prompt notification by health care facilities for cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

Constitutional Issues

The record developed during the Commission's two hearings and continuing investigation demonstrates that there is a grave danger to the constitutional rights of newborn children in cases where food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. The principle of equal protection of the laws is offended when disability is the basis of a nontreatment decision. Procedural protection for the interests of both child and parents is often absent completely or is woefully inadequate to the task of sifting the facts.

Since the Supreme Court's decision in *Bowen v. American Hospital Association,* it has been clear that judicial action is insufficient to protect newborn children with disabilities. The task of protecting such children from discrimination and neglect, whether based on ignorance or outright prejudice, thus falls to Congress and to the State legislatures.

Incidence of Discriminatory Denial of Medical Treatment

A significantly high incidence of medical discrimination against children with disabilities exists that is part of a much larger pattern of medical care discrimination against people with disabilities. This incidence largely persists despite 3 years of experience under the Child Abuse Amendments. The Commission relied on specific cases; testimony at the Commission's hearings, including the testimony of people with disabilities and their relatives; the repeatedly declared views of physicians set forth in professional journals; surveys of health care professionals; and investigative reporting.

Enforcement of Child Abuse Amendments by the Child Protective Services Agencies

Principal enforcement responsibility for the Child Abuse Amendments resides with State child protective services (CPS) agencies, the variously named entities that exist to administer each jurisdiction's child abuse and neglect laws. Under current law, the fate of children with disabilities who are threatened with denial of lifesaving medical treatment, food, and fluids largely depends on how effectively CPS agencies carry out this responsibility. Alternative avenues of protection are scarce. Direct Federal efforts to prevent this type of medical discrimination to date have been stymied.

The close working relationship between some CPS personnel and members of the medical profession has resulted in the substantial failure of many State child protective service agencies to effectively enforce the child Abuse Amendments.

CPS Delegation of Investigative Responsibility

Virtually all jurisdictions receive Federal funds from the Department of Health and Human Services under the Child Abuse Prevention and Treatment Act. A review of their policies and procedures has shown that on their faces, the policies of 14 of these States explicitly abdicate to internal hospital infant care review committees or hospital staffs the authority to decide whether illegal denial of treatment is taking place when a report of suspected denial of treatment is received by the State agencies.

Under the Child Abuse Amendments, agencies must make the determination whether treatment is medically indicated. The existence of hospital-administered infant care review committees (ICRC) does not relieve a State CPS agency of its responsibility to investigate suspected cases of withholding of medically indicated treatment or to employ its legal authority to prevent such withholding. The widespread readiness of CPS agencies to surrender their arms-length oversight responsibility concerning medical neglect appears in part to be rooted in the special relationship that has developed between CPS workers and members of the medical profession. In dealing with traditional forms of child abuse and neglect, CPS agencies rely primarily on health care professionals for diagnosis and reporting.

In contrast to the receptivity of most CPS agencies to views from medical organizations, views from disability organizations—the groups representing those whom the amendments were designed to protect—are ignored in many cases. According to one survey of 37 responding jurisdictions, 34 said that they had consulted with medical representatives in formulating their implementing procedures, while only 11 said they had consulted with disability groups.

Failure to Comply with Federal Regulations

In direct contravention of Federal regulations, six States' CPS agencies have no written policy specifying how they would obtain medical records to investigate a report of medical neglect. Four States' CPS agencies have policies that fail to provide for securing an independent medical examination of a child with a disability about whom a report of a suspected medical neglect has been filed. The impression that some States pay little or no attention to the standards of treatment embodied in the Federal law and regulations is reinforced by the fact that eight States' CPS agencies have policies that either misdefine the term "withholding of medically indicated treatment," do not define it at all, or define the term in such an abbreviated fashion as to invite ambiguity and uncertainty.

Many States are not even clear in their policies concerning who is covered by the standards of treatment in the act. Twenty-two State CPS agencies have policies that either do not define the term "infant" or—in direct contravention of the governing regulations—define the term to encompass only infants of less than 1 year in age.

CPS agencies are part of the State government, often in the same department that runs hospitals and other institutions that provide medical treatment to children with disabilities. This can create a direct conflict of interest.

Infant Care Review Committees

Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments, and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

At the same time, it is clear that such committees are here to stay. Therefore, the Commission believes there is a need to ensure that there be independent, contemporaneous scrutiny of infant care review committee proceedings, preferably by medically knowledgeable and experienced disability advocates, and that the prompt reporting requirement be more vigorously enforced to make this possible.

The establishment of infant care review committees—internal hospital committees that consider instances in which life-preserving medical treatment is being or may be withheld from infants with disabilities—is encouraged by the Child Abuse Amendments, as it was by the section 504 Final Rule. A 1986 survey found that 51.8 percent of hospitals with either a neonatal intensive care unit or over 1,500 births annually had established such committees, and an additional 8.9 percent were in the process of forming them. The proponents of ethics committees attempt to shift the question from the substantive one of whether treatment should be withheld to the procedural one of who should decide whether treatment should be withheld.

The Final Rule of section 504 includes a recommendation that hospitals establish infant care review committees. However, HHS recognized that the original rationale for ethics committees stood in stark contrast to the approach embodied in the nondiscrimination tenets of section 504. Inherent in reliance on section 504 was the assumption that the law establishes a societally defined basis for determining when life-preserving treatment must be provided to children with disabilities and when it may be withheld from them. In contrast, inherent in the original rationale for ethics committees was the assumption that such determinations should be decided on a case-by-case basis varying from hospital to hospital. Because of this dichotomy, the Final Rule explained that HHS revised a model proposed by the American Academy of Pediatrics "to underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504."

HHS guidelines assumed that the particular cases that came before a committee would not involve relitigation of the ethical and social debates about the propriety of treatment that preceded enactment of the law, but would instead focus on an analysis of how the law should properly be applied to the facts of that case. The "ethical issues" concerning what circumstances justify withholding of treatment would not be reconsidered on a case-by-case basis. The issues were to be regarded as settled by the Child Abuse Amendments.

Infant Care Review Committees in Action

Are the infant care review committees serving as prognosis committees, providing advice concerning whether or not the facts in particular cases bring them within the circumstances the Child Abuse Amendments define as requiring treatment? Or do they act as "ethics" committees, making quality of life judgments about whether or not treatment should be withdrawn without reference to detailed legal standards—the role originally envisioned for them by the President's Commission and the American Academy of Pediatrics? It appears that the vast majority of committees convene only to deal with disagreements and do not make an attempt to scrutinize most denial of treatment decisions to ascertain whether they comply with the law. This implies that many hospital infant care review committees seem more attuned to diffusing and resolving conflict in a way that keeps any controversy as much as possible within hospital walls than to ensuring that children with disabilities receive the lifesaving treatment to which they are entitled.

Even before the passage of the Child Abuse Amendments, the Federal regulations implementing the Child Abuse Prevention and Treatment Act required States receiving Federal funding for their child protective services programs to "provide by statute or administrative procedure that all other persons are permitted to report known and suspected instances of child abuse and neglect to a child protective agency or other properly constituted authority." The implementing regulations for the Child Abuse Amendments establish that States receiving Federal funds must ensure that health care facilities designate individuals with the duty to notify promptly the State child protective services agency of all "cases of suspected medical neglect (including instances of the withholding of medically indicated treatment from disabled infants with life-threatening conditions)."

Because not merely known but also "suspected" instances must be reported, the health care facility's obligation to notify the State agency is not limited to cases in which, for example, the infant care review committee or the responsible hospital official makes a final determination that illegal withholding of treatment is occurring or about to occur. Nor is it limited to cases in which the infant care review committee or the responsible hospital official has attempted to obtain treatment but has failed and is turning to the civil authorities as a last resort.

Limitations of Hospital Self-policing

It is questionable whether most committees are constructed in a manner that permits searching scrutiny of proposed denials of treatment. Infant care review committees, although they upon occasion have "outside" members, represent an approach to the "Baby Doe" problem that relies essentially upon the internal self-regulation of the health care community. The Department of Health and Human Services and the American Academy of Pediatrics recommend that committees include representatives of disability groups. A 1986 survey found that, of the responding hospitals, less than a quarter of the committees—23.9 percent—had a disability group representative.

A preponderance of medical personnel on committees does not necessarily mean that they are especially well equipped to serve as prognosis committees. Ethics committees are largely insular bodies, sharing the mores and limitations of knowledge of the local hospital. A reluctance to criticize one's colleagues, let alone report their decisions to a State agency, is only natural in such a setting. Resort to infant care review committees presents the same problem generally applicable to the creation of an internal body as a means of showing the public that the institution is serious about correcting abuses: an institution rarely does a good job of policing itself. Outside oversight is needed.

Federal Government

The Commission is dismayed at the extremely poor performance of the Department of Health and Human Services in fulfilling its responsibilities to protect children with disabilities from medical discrimination, first under section 504 of the Rehabilitation Act in the time period before its use was enjoined, and currently under the Child Abuse Amendments of 1984. That performance requires substantial improvement.

Although the Commission is encouraged by steps the Office of Human Development Services of the Housing and Human Services Department now states it will take in response to this report, it is too soon to determine whether this will result in a very significant increase in scrutiny of the performance of recipient State child protective services agencies that is essential if the Department is to fulfill effectively its responsibilities under the law.

Responsibility for enforcing section 504 rested with the Office for Civil Rights (OCR) in the Department of Health and Human Services. In none of the cases OCR investigated—even the Bloomington Infant Doe case—did it make a public finding that a section 504 violation occurred. If a discriminatory denial of treatment was found, OCR asked for assurances that practices would be changed to achieve compliances. If it received them, it did not make a public "finding of discriminatory withholding of medical care." In theory, OCR might detect noncompliance in fact and secure remedial action by the discriminating party, thus fulfilling its role, without officially reporting a finding of noncompliance.

In at least two instances known to the Commission, OCR delayed taking action. Confronted with substantial evidence of significant and ongoing denial of lifesaving treatment to children with disabilities, evidence that suggested an ongoing threat to lives in both States, OCR failed to act with the vigor and dispatch incumbent on it in light of the circumstances, let alone consistent with its legal responsibilities and its publicly stated position.

Although several State Child Protective Services agencies failed to meet the standards and procedures required under the Child Abuse Amendments and their implementing regulations, the States have been certified by HHS for receipt of Federal funds under the Child Abuse Prevention and Treatment Act, without being advised that they are out of compliance or being given any deadline to bring their standards and procedures into compliance. The Commission considers this a significant failing on the part of HHS.

In a report on infant care review committees, the HHS Office of the Inspector General identified between 20 and 36 potential Baby Doe cases considered by 10 committees whose activities were monitored. Only three cases were reported to State CPS agencies. The Office of Inspector General did not review the facts in the unreported cases to determine whether or not they met the standards established in the Child Abuse Amendments. It is hard to see how, without doing this, the Department could accomplish its task of ascertaining whether the committees are fulfilling what HHS has described as "the role of the ICRC [infant care review committee] to review the case. . .and recommend that the hospital seek CPS agency involvement when necessary to assure protection for the infant and compliance with applicable legal standards."

The Protection and Advocacy System: A Resource for Enforcement

In 1975 Congress established structures called Protection and Advocacy Systems (P&A), originally attuned specifically to the need to ensure vigorous advocacy of the rights of persons with developmental disabilities. The Developmentally Disabled Assistance and Bill of Rights Act required that each State or similar jurisdiction receiving Federal funding for persons with developmental disabilities establish an independent system with "authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of [persons with developmental disabilities]."

In 1984, in substantially expanding funding for the P&A systems, Congress recognized both their importance and their impressive track record. The Senate Committee on Labor and Human Resources Report noted that P&As are an expanding effort by Congress to assure disabled persons protection of their rights under law. In 1986 Congress chose "to build on the experience of the existing P&A System in investigating and resolving situations involving abuse and neglect" of persons with mental illness by adding responsibility for advocacy for this population to the P&As.

The Commission thinks that the P&A system affords an experienced and appropriate resource to remedy discriminatory denial of medical treatment, food, and fluids to people with disabilities. P&As currently have a general jurisdiction that encompasses such instances. The Commission believes that the P&A system should be brought into active involvement in efforts to prevent illegal denial of treatment to children with disabilities. In summary, the Commission envisions the following approach:

- Prompt reports of suspected or actual cases of withholding of medically indicated treatment would still go to CPS agencies, which would retain the authority and responsibility to investigate them. However, the State P&A agency would be notified by the CPS agency as soon as the report was received. The P&A would have access to records. As a representative of the interests of the child, the P&A agency would have independent authority, similar to that now held by the CPS agency, to obtain medical records and to obtain a court order.
- To catch cases not being reported to the CPS agency, any hospital that uses a committee to review a prospective withholding of treatment from a person with a disability would be required to notify the State P&A agency of meetings held to discuss the case. The P&A would be able to review the records and discuss the situation. A court order could be sought by the P&A.
- To provide a deterrent to physicians disposed to not reporting a case to the State CPS agency or a hospital committee, the P&A could conduct retrospective reviews of the medical records.

The Commission sees several advantages to involving the P&A systems more directly in the enforcement of the Child Abuse Amendments of 1984. First, the P&A system has more specialized experience in safeguarding the rights of persons with disabilities than the CPS system. While the CPS system deals with the abuse and neglect of all children, most of whom are not disabled, the P&A system since its inception has concentrated on protecting the rights of persons with disabilities. Second, the P&A system is less likely to be affected by conflicts of interest than the CPS system because the P&A system is statutorily independent of State agencies and hospitals. Third, unlike the reliance by the CPS agencies on the medical profession, P&A agencies have no special relationship with the medical profession that could impair their ability to be vigorous advocates. Fourth, P&A agencies are accountable to the populations they serve. They must provide an annual opportunity "to assure that persons with developmental disabilities have full access to services of the system." This provision for oversight, not present in most CPS agencies, is an important check on the danger of relaxing the vigilance and vigor essential to effective advocacy.

The Commission believes that appropriate additional funding for the P&As will be needed to implement these new responsibilities. It should be adequate both for State-by-State implementation and for supportive training and technical assistance, including resources for the rapid evaluation of medical conditions. With these powers and resources, the P&A system would be in a position to bring about what the Commission believes would be a significant improvement in enforcement of the medical treatment rights of persons, especially children, with disabilities.

Findings and Recommendations

Based on its hearings, research, and the report, the Commission adopts the following findings and recommendations.

General Findings

1. Surveys of health care personnel, the results of investigative reporting, the testimony of people with disabilities and their relatives, and the repeatedly declared views of physicians set forth in their professional journals all combine to persuade the Commission of the likelihood of widespread and continuing denials of lifesaving treatment to children with disabilities.

2. The Commission is convinced that the evidence supports a finding that discriminatory denial of medical treatment, food, and fluids is and has been a significant civil rights problem for infants with disabilities. It is also persuaded that the available evidence strongly suggests that the situation has not dramatically changed since the implementation of the Child Abuse Amendments of 1984 on October 1, 1985.

3. The grounds typically advanced to support denial of lifesaving medical treatment or food and fluids are based on erroneous judgments concerning the quality of life of a person with a disability or on social judgments that such a person's continued existence will impose an "unacceptable" burden on his or her family or on the Nation as a whole. These judgments are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities.

4. Many people, including members of the medical profession, hold negative attitudes about life with disability that affect not only children but also adults with disabilities. Moreover, direct testimony was provided at the Commission hearings that these attitudes exist and that discrimination in the provision of lifesaving and other medical treatment occurs with respect to adults with disabilities as well as in cases involving infants and children. Further fact-finding is needed to determine the extent of discriminatory denial of medically indicated treatment in cases involving adults with disabilities.

5. There is evidence that in many instances in which lifesaving treatment is denied to children with disabilities, their parents are only nominally making the decision to withhold the treatment. In practice the doctors are often the prime movers in denying the treatment.

6. The question of whether children with disabilities should be denied lifesaving treatment has frequently been couched in popular debate as though the issue were the wisdom of government intrusion into matters of parental discretion. In fact, however, for decades the universally accepted law has been that when parents make treatment decisions that will undebatably lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating provision of lifesaving medical care. It is only when the children have disabilities that the claim of parental autonomy is given serious sympathetic consideration. Thus, the decisions upholding putative parental decisions to deny lifesaving treatment to their children with disabilities are rooted less in a respect for parental authority than in a bias against disability.

7. There are substantial economic costs associated with some forms of disability. Many costs, however, are less a function of the disability or the severity of the disability than of a policy that tends to segregate and isolate, at enormous public cost, those persons considered most severely disabled without even considering the alternative of providing social and economic support for the family. The assumptions influencing denial of treatment have often been: (1) that the level of severity of disability is the major determinant of lifetime costs; (2) consequently, that the more severely disabled a child may appear to be at birth the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency; and (3) therefore, the more expensive it will be to meet that person's basic needs. Although these assumptions rest on major fallacies, reliance on them has resulted in a self-fulfilling prophecy: a diagnosis of severe disability at birth leads to placements in residential and nonwork environments that significantly limit that person's capability and entail far more expense than necessary. The ultimate irony occurs when the expense that is the consequence of the original unfounded and stereotypical assumption becomes a basis for ending the lives of persons with severe, or what are thought to be severe, disabilities shortly after they are born.

8. The record developed during the Commission's two hearings and continuing investigation demonstrates that there is a grave danger to the constitutional rights of newborn children in cases in which food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. The principle of equal protection of the law is offended when disability is the basis of a nontreatment decision. Procedural protections for the interests of both child and parents are often absent completely or are woefully inadequate to the task of sifting the facts.

General Recommendations

1. The Commission concludes that the Congress and the President should address the very real problems faced by people with disabilities and their families. The President should take the lead in fostering the development of a climate of social acceptance of persons with disabilities and their families by speaking publicly on the issue. The President should instruct the White House Council on Domestic Policy to review the adequacy, as well as the coordination and development of, supportive services intended to assist such families. The President should order a review of the mechanisms designed for vigorous enforcement of the statutory rights of those with disabilities to accessible and integrated transportation, housing, education, health care, and employment. In addition, the appropriate committees of the Congress should schedule hearings to address these questions.

2. In considering legislation designed to prevent discrimination against persons with disabilities, Congress should take care to make clear that discrimination in the course of rendering medical treatment is precluded.

3. There is a need for factfinding activities by the Congress, the State legislatures, and Federal, State, and local agencies charged with the enforcement of civil rights laws and medical standards, to determine the extent to which adults with disabilities are subjected to discrimination in the provision of medical care and treatment, and to evaluate what remedies exist or are needed to prevent future discrimination of this kind from taking place. In particular, the new Secretary of Health and Human Services should direct the Department to undertake such a study.

Specific Findings Regarding Support for Families with Disabilities

1. The period surrounding birth is a time of considerable stress and emotion, and for nondisabled parents the birth of a child with a disability typically comes as a great shock. While beset by traumatic feelings of depression, grief, anger, and guilt, many such parents today have inadequate accurate information with which to make considered evaluations concerning the nature of life with a disability or the consequences for a family that includes a child with a disability.

2. One of the principal motivations for denial of lifesaving treatment to children with disabilities is the view that their continued existence will create too great a burden for their families. There is evidence that this concern has led to concurrence or acquiescence in the death or elimination of these children.

Specific Recommendations Regarding Support for Families with Disabilities

1. Congress should amend the Medicaid Act or other appropriate legislation to require that recipients of Federal financial assistance for medical services provide specific information on support and resources to parents of newborn children with disabilities. This should include information on adoption and, when necessary, information on other supported family placement with resources necessary to care for the child.

2. Congress should amend the Medicaid Act or other appropriate legislation to lower the adjusted gross income ceiling that a family must spend on disability-related medical expenses before the family member with a disability becomes medicaid eligible.

Specific Findings Regarding Section 504 of the Rehabilitation Act of 1973

1. The hearings and research conducted by the Commission, and the findings based on them, especially General Finding 5, supply a factual record that was absent in 1986 when the United States Supreme Court decided *Bowen v. American Hospital Association,* striking down regulations intended to assist enforcement of section 504 in the context of discriminatory denial of treatment to children with disabilities.

2. A central problem with the *Bowen* plurality opinion is that it suggests that section 504 puts no constraints on a recipient of Federal financial assistance responsible for the discriminatory denial of treatment to a person with a disability, if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child's medical treatment.

3. The Commission's findings suggest that parents who authorize denial of treatment to their children with disabilities are frequently substantially influenced in that decision by the views of their children's'physicians and other health care personnel who frequently display inadequate awareness of the potential of these children.

4. In cases in which decisions nominally made by parents to deny treatment to children with disabilities are in fact generated by health care personnel, health care providers who do not provide lifesaving medical treatment to children with disabilities that would be provided were it not for the disabilities should be held to violate section 504 despite parental acquiescence in the treatment denial.

5. The logic of the *Bowen* plurality opinion applies equally to authorizations for denial of treatment by other nonrecipient surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions.

6. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities. In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient's involvement, would be prohibited discrimination. A recipient's substantial involvement in a nonrecipient's discriminatory practices should be held to violate section 504.

7. The Commission's reading of the legislative history and plain meaning of section 504 of the Rehabilitation Act of 1973 persuade it that the provision does cover discriminatory denial of medical treatment to people with disabilities.

8. The Commission concludes that passage of the Civil Rights Restoration Act establishes that a hospital's practice of reporting to State agencies instances in which parents withhold consent for provision of lifesaving treatment to their children is covered by section 504. The act defines section 504's coverage to include "all of the operations of. . .an entire corporation, partnership, or other private organization. . .which is principally engaged in the business of providing. . .health care. . . ." If a hospital engages in reporting cases of medical neglect to the State child protective services agency, that practice of reporting is among the operations of a corporation that principally provides health care. Therefore, if any part of the hospital receives medicaid or medicare, discrimination in reporting based on handicap (such as a practice of reporting instances in which religiously motivated parents refuse consent for lifesaving treatment for nondisabled children to the authorities, but failing to report instances in which parents refuse consent for lifesaving treatment for children with disabilities) violates section 504.

9. During the period in which enforcement of section 504 in this context was not yet enjoined, the performance of the Office for Civil Rights of the Department of Health and Human Services in implementing it was poor. Confronted with substantial evidence of significant and ongoing denial of lifesaving treatment to children with disabilities, evidence that suggested an ongoing threat to lives in two States, the responsible Federal agency failed to act with the vigor and dispatch incumbent on it in light of the circumstances, its legal responsibilities, and its publicly stated position.

Specific Recommendations Regarding Section 504 of the Rehabilitation Act of 1973

1. In light of the record developed by this Commission, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends that the Executive branch give careful consideration to resuming investigation of allegations that children with disabilities are discriminatorily denied medical treatment based on handicap and initiate enforcement of section 504 in cases in which the allegations are found to be justified.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to make clear that withholding of medically indicated treatment, as defined in the Child Abuse Amendments of 1984, constitutes denial of the benefits of health care services for purposes of Title VI and section 504.

Specific Findings Regarding the Child Abuse Amendments of 1984

1. The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care which States that receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

2. Parents engaged in life and death decisions for their children are heavily dependent on the good faith of, and accurate information provided by, those advising them. Because advisors may be ignorant or prejudiced about persons with disabilities, there is a need for the establishment of a broadly based advisory process that includes members of the local protection and advocacy system (P&As) and others with expertise in disability and rehabilitation. Establishment of a structured care review process or committee will ensure that the decision made is in compliance with the standards set forth in the Child Abuse Amendments, provided that any participant in the advisory process who is concerned with the well-being of the child has standing to invoke the remedies that are otherwise available under State law and the Child Abuse Amendments for dealing with child neglect.

3. Many State child protective services agencies rely heavily upon members of the medical profession for information and assistance concerning cases of parental child abuse. This close working relationship has also led to heavy reliance by many State child protective services agencies on the very medical care facilities and personnel whose actions, advice, or neglect are at issue in cases of suspected medical care discrimination. Taken together, such close working relationships among State child protective services agencies and members of the medical profession has resulted in the substantial failure of many such agencies to enforce effectively the Child Abuse Amendments of 1984.

4. It is questionable whether most hospital-based ethics or infant care review committees are constructed in a manner that makes them likely to conduct searching scrutiny of proposed denials of treatment. They represent an approach that relies essentially upon the internal self-regulation of the health care community. Few committees include representatives of disability rights groups; the majority convene only to deal with disagreements, rather than attempting to scrutinize most denial of treatment decisions to see whether they comply with the law. Instead of strictly applying the Child Abuse Amendment standards, many appear in practice to use more ambiguous criteria that include consideration of the projected "quality of life" of the child with a disability. Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

5. The Commission is dismayed at the poor performance of the Office of Human Development

Services of the Department of Health and Human Services in fulfilling its responsibility to ensure that State child protective services agencies receiving funds under the Child Abuse Prevention and Treatment Act comply with the Child Abuse Amendments of 1984 so as to protect children with disabilities from illegal discrimination in the provision of medical care. That performance requires substantial improvement. Although the Commission is encouraged by steps the Office of Human Development Services now states it will take in response to this report, it is too soon to determine whether they will result in the very significant increase in scrutiny of the performance of recipient State agencies that is essential if the Department is effectively to fulfill its responsibilities under the law.

Specific Recommendations Regarding the Child Abuse Amendments of 1984

1. Because funds available under the Child Abuse Prevention and Treatment Act are apparently not sufficient to induce all jurisdictions to comply with the Child Abuse Amendments in order to qualify for them, compliance with the Child Abuse Amendments should be made an additional requirement for State eligibility for participation in medicaid, so that the protections they afford will be made available to all children with disabilities in the United States.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to establish a mechanism to improve reporting of cases of suspected withholding of medically indicated treatment by requiring that any hospital that uses a committee to review a prospective instance of withholding of treatment from a person with a disability is required to notify the State protection and advocacy (P&A) agency of meetings held to discuss the case. The P&A agency should then be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee. It should have authority to obtain a court order for an independent medical examination, and if it concludes that medically indicated treatment would otherwise be withheld illegally, it should have the standing to institute a court proceeding to require that it be provided.

3. Hospitals without a specialized advisory process for dealing with the special needs of parents for information on disability and rehabilitation should be required to establish a process in accordance with the provisions of the Child Abuse Amendments and the recommendation made above.

4. Representatives of the local protection and advocacy system should be included in the advisory process, both as advocates for the child's interests and as a resource for the information of the parents.

5. Congress should amend section 504 and the Child Abuse Amendments to require the establishment of such a care review process or committee within treatment facilities across the country.

6. Should any participant in a care review advisory process not be satisfied that the outcome of the process is in compliance with the standards set forth in the Child Abuse Amendments, that person should have standing to invoke such remedies, judicial or otherwise, that are available under State law for dealing with child neglect.

7. When a State child protective services agency (CPS) receives a report of suspected withholding of medically indicated treatment under the Child Abuse Amendments, it should be required promptly to notify the State P&A agency and to provide it access to the records obtained and information developed by the CPS agency. As a representative of the interests of the child, the P&A agency should have independent authority, similar to that now held by the CPS agency, to obtain medical records, to obtain a court order for an independent medical examination, to appear on behalf of the child in any court proceeding to authorize medical treatment initiated by the CPS agency. The P&A agency should also have independent standing to initiate a court proceeding to authorize medical treatment for the child.

8. To create a deterrent to physicians who not only might fail to report a case of withholding to the State CPS agency but also might not submit it to a hospital committee, the P&A agency should be given authority to conduct retrospective reviews of the medical records of those with disabilities who die in the State. If instances of illegal withholding of medical treatment are detected, the P&A agency should be able to seek appropriate action by licensing boards or Federal funding sources and, in extreme cases, to institute suits for injunctive or monetary relief or refer cases for investigation by prosecuting attorneys.

9. Congress should afford P&A agencies appropriate financial and backup assistance to enable them to fulfill these roles capably.

10. The Office of Human Development Services in the Department of Health and Human Services should take corrective measures to ensure more rigorous scrutiny of State plans submitted for funding under the Child Abuse Prevention and Treatment Act to remedy the current widespread failure of State child protective services agencies to comply with the requirements of the Child Abuse Amendments of 1984.

Chapter 1

Fundamental Rights: An Introduction to Medical Discrimination Against People with Disabilities

The Chairman opened the first hearing the United States Commission on Civil Rights held on the subject matter of this report by setting forth the Commission's aim:

> The purpose of this hearing is to attempt to determine the nature and extent of the practice of withholding medical treatment or nourishment from handicapped infants and to examine the appropriate role for the Federal Government.
>
> Section 504 of the Rehabilitation Act of 1973, as amended, prohibits discrimination against qualified handicapped individuals under any program or activity receiving Federal financial assistance. In the spring of 1982, reports of the death of a Bloomington, Indiana, infant with Down's syndrome, from whom available surgical treatment to correct a detached esophagus was withheld, prompted widespread attention on the medical treatment of handicapped newborns. Following the Indiana incident, the Department of Health and Human Services [HHS] issued a notice to recipient hospitals reminding them of the applicability of section 504 to the treatment of handicapped infants. HHS then issued interim and proposed rules governing nondiscrimination in the treatment of these newborns, both of which were challenged in courts and struck down.
>
> Last fall Congress passed the Child Abuse Amendments of 1984, requiring States seeking child protection funds from the Federal Government to take certain steps to protect handicapped newborns. HHS has issued rules and model guidelines under that statute which have been made final and will become effective in October of this year.
>
> The primary focus of this hearing is the role the Federal Government should play. . . .[1]

One year later, the Commission held a second hearing to receive testimony concerning the Supreme Court's decision in *Bowen v. American Hospital Association*,[2] which invalidated regulations issued by HHS to implement section 504, and to examine the manner in which the regulations promulgated under the Child Abuse Amendments had been implemented in the period since the first hearing.

Underlying both sets of hearings, and thus this report, is concern about the appropriate role of the Federal Government in safeguarding the rights of children with disabilities under both section 504 and the Child Abuse Amendments of 1984 to be free of discrimination in the provision of lifesaving medical treatment. Three years have passed since the regulations implementing the Child Abuse Amendments took effect, and two and a half years have passed since the section 504 regulations were rendered unenforceable by *Bowen*. Thus, in evaluating the performance of the Federal Government in addressing the statutory rights of children with disabilities to lifesaving medical treatment, this report raises the question whether modifications to current laws and practices are desirable.

Included in the Commission's mandate is the responsibility to appraise the laws and policies of the Federal Government and to examine legal developments with respect to discrimination or denials of equal protection of the laws under the Constitution because of handicap.[3] This report focuses solely on questions of discrimination. It addresses medical services that are already provided or required to be provided to nondisabled individuals but that are withheld from individuals with disabilities precisely because of the disabilities.[4] It is neither the province nor the purpose of the Commission to oversee, evaluate, or question the exercise of legitimate medical judgment that is inherent in decisionmaking concerning medical treatment. The Commission emphatically disclaims any competence or intention to judge whether particular medical treatments are more efficacious than others or at what times a medical treatment is effective or futile. Such judgments in individual cases may be correct or they may be mistaken. They may raise questions appropriate for examination through peer review, licensing boards, or malpractice cases; but they do not entail civil rights issues.

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[1] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 1-2 (1985) (vol. I) (statement of Clarence M. Pendleton, Jr., Chairman, U.S. Commission on Civil Rights).

[2] 476 U.S. 610 (1986).

[3] 42 U.S.C.A. § 1975c (West Supp. 1988).

A civil rights issue appropriate for examination by this Commission arises in the context of medical treatment decisionmaking only when such decisionmaking is influenced by factors extraneous to the science and art of medicine: when color, race, age, handicap, or national origin lead to a difference in treatment despite being irrelevant to the bona fide medical judgment.[5] If kidney dialysis, for example, is withheld from someone because it is medically contraindicated, such a judgment is outside the scope of the Commission's purview. But if medically indicated kidney dialysis is withheld from a person with a disability precisely because of the disability (and the disability itself does not make provision of the dialysis ineffective or dangerous), that raises a civil rights issue suitable for consideration by the Commission.

A number of well-publicized cases has raised concern that discrimination based on disability may be occurring in the provision of health services.[6] Reports of such cases convinced the Commission to undertake consideration of the laws that do and should govern, of the prevalence and context of discriminatory practices, of the effectiveness of past and present Federal Government activity in this field, and of options for future Federal Government policies.

Oklahoma Case

Denial of treatment practices at Children's Hospital of Oklahoma[7] is currently the subject of a lawsuit brought by the American Civil Liberties Union and the National Legal Center for the Medically Dependent and Disabled on behalf of Carlton Johnson.[8] The black child of a "welfare mother," he was allegedly left to die by hospital staff at a "children's shelter" after he was born with spina bifida.[9]

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[4] Preexisting child abuse and neglect laws throughout the States create the obligation to provide children lifesaving medical treatment. See chap. 5. The statutory or constitutional rights of children with disabilities to receive equal treatment are found in section 504 of the Rehabilitation Act of 1973 (29 U.S.C.A. §794 (West 1985)), the Child Abuse Amendments of 1984 (42 U.S.C.A. §§5101–03 (West Supp. 1988), and the due process and equal protection clauses of the 14th amendment (U.S. Const. amend. 14 §1). Section 504, considered in chap. 6, is explicitly an antidiscrimination statute; given a preexisting program or activity receiving Federal financial assistance, handicap cannot be the sole basis for someone's being excluded from the program, denied benefits under the program, or otherwise subjected to discrimination in the program. While the Child Abuse Amendments of 1984, considered in chap. 7, define an explicit standard of medical care for children with disabilities, they do so in the context of a system that has been universally applied to require similar care for children without disabilities. The equal protection clause, considered in chap. 8, creates a nondiscrimination standard applicable when a state actor that provides medical care or legal protection to those without disabilities unwarrantably denies it to those with disabilities precisely because of the disabilities. The constitutional procedural due process rights also considered in chap. 8 presuppose an existing substantive benefit which they ensure may not be denied by processes that fail to meet standards of fundamental fairness.

[5] "A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment." United States v. Univ. Hosp., State Univ. of New York at Stony Brook, 729 F.2d 144, 162 (2d Cir. 1984) (Winter, J., dissenting).

[6] Some of these cases also raise the concern that, within the class of people with disabilities, discrimination may also be occurring based on economic status or social class. Frank Bowe, director of the American Coalition of Citizens with Disabilities, testified: "[I]t has been shown again and again. . .that persons who are disabled who are members of minority groups are denied an education or are denied medical care or denied any kind of opportunity to get vocational training." U.S. Commission on Civil Rights, Civil Rights Issues of Handicapped Americans: Public Policy Implications 39 (1980) at 28–29.

[7] At the time of the alleged events that are the subject of the lawsuit, the hospital was named Oklahoma Children's Memorial Hospital.

[8] Paulus, *Suit Filed in Oklahoma Alleging Twenty-Four Infants Died After Being Denied Beneficial Medical Treatment*, 1 Issues in L. & Med. 321, 324–25 (1986). Amended Complaint, para. 78, at 13, Johnson v. Gross, No. CIV–85–2434–A (W.D. Ok. filed July 14, 1987).

[9] Spina bifida, also known as myelomeningocele or meningomyelocele, is a congenital disability consisting of a gap or improper opening through the vertebrae of the spinal column. It results from a failure of the developing spinal cord to roll into a completely tubular structure during the early stages of pregnancy. Spina bifida manifesta, also called spina bifida aperta, results when the spinal cord or some of the nerve tissue lining surrounding the cord extend through the opening in the verte-

Carlton Johnson was evaluated by a medical team using a procedure under which, as described in an earlier medical journal article, 24 out of 69 babies analyzed were denied surgery and died.[10] Infants born with spina bifida were evaluated by a "myelomeningocele team" shortly after birth. In this evaluation, the team members wrote, they were "influenced" by a quality of life formula: $QL = NE \times (H+S)$. In this formula:

> QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society.[11]

Based on the assessment, the team recommended to the parents that the infant be given either vigorous or supportive care. Vigorous care involved, at a minimum, closing the spinal lesion. Supportive care, by contrast, consisted of a "regular follow-up. . .until death or until a decision to treat the child more aggressively is made."[12] The team members acknowledged that "treatment for babies with identical [degrees of mental and physical disability] could be quite different, depending on the contribution from home and society."[13]

In the case of Carlton Johnson, the medical record stated:

> "neurosurgery [was] not enthusiastic about shunting the child and closing the defect." The medical records stated that information was given to Sharon Johnson, his mother, and that she would make the final decision between treatment and nontreatment. Ms. Johnson, however, said that "the only thing they told me was about a shunt, and this, you know, after they told me about six months, that he would live six months without it, and then with it, a year, and I just figured, what's the sense in—he already suffers, so why should he suffer anymore?"[14]

Carlton was accordingly sent to a children's shelter, where he developed severe respiratory distress, periods of cessation of breathing, an ear infection, and dehydration. When he was returned to Children's Hospital of Oklahoma:

> Physician's orders stated that there were to be no laboratory tests to monitor his condition, no intravenous fluids to correct the dehydration, and no antibiotics for the ear infection. If Carlton were to suffer a cardiopulmonary

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brae. The protruding tissues often form a fluid-filled sac on the infant's back. In 96 percent of the cases of spina bifida manifesta, the spinal cord itself protrudes through the gap in the vertebrae. Spina bifida involves various degrees of (1) muscle weakness and paralysis below the opening; (2) sensory loss below the opening; (3) hydrocephalus [*see* note 14, *infra*] in about 70 percent of the cases; and (4) bowel and bladder incontinence. H. Swinyard, The Child with Spina Bifida 5 (1980).

According to Dr. David McLone, head of Pediatric Neurosurgery at Chicago Children's Memorial Hospital, "Spina bifida has been referred to as the most complex disease which is compatible with survival." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 6 (vol. I) (1985). At least 6,000 children are born with spina bifida each year in the United States. *Id.*

Dr. McLone testifed concerning the typical technical context of treatment decisions concerning spina bifida:

> The problem arises that if they are not operated on within a few days of life, they will acquire a potentially lethal infection, and if they are left unoperated on, approximately half of the children, in most studies, will die. If their back is repaired and closed, then about 90 percent of the children will go on to develop rapidly progressive hydrocephalus and require a second operation to install a shunt, a small tube to drain the fluid from their brain into another brain cavity.

Id. at 6. *See* note 14 *infra* for a discussion of hydrocephalus.

[10] Gross, Cox, Tatyrek, Pollay, & Barnes, *Early Management and Decision Making for Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983).

[11] *Id.* at 452.

[12] *Id.* at 454.

[13] *Id.* at 456.

[14] Paulus, *supra* note 8, at 324. Sherwood, *Who Lives, Who Dies?—Part 1*, Cable News Network Documentary (Feb. 21, 1984).

Hydrocephalus—which can occur in combination with spina bifida or independently–is an abnormal accumulation of fluid in the ventricles (cavities) of the brain. It results from an imbalance between production and absorption of cerebrospinal fluid that flows through the brain and spinal cord. Normally the fluid is produced by cells in the ventricles, passes to the outer surface of the brain and to the spinal cord, and is eventually absorbed into the bloodstream. When the pathways for cerebrospinal fluid flow are obstructed or incomplete, production exceeds absorption and the fluid pressure can build up. Increased fluid pressure in the brain can cause enlargement of the head, compression of the brain, prominence of the forehead, mental deterioration, and convulsions. The compression of the brain can be so severe that an X-ray will show only a thin ribbon of brain tissue pressed up against the inside of the skull. Swinyard, *supra* note 9, at 18. Hydrocephalus without spina bifida has a mortality rate of 50 to 60 percent if untreated. March of Dimes Birth Defects Foundation, Incidence of Selected Birth Defects 2 (1984).

Shunting is the primary treatment for hydrocephalus. It consists of the implantation of a flexible tube (the shunt) into a ventricle of the brain to permit drainage of the excess fluid. The tube is passed through a small opening in the skull and then underneath the skin from the head to some other part of the body. The drainage end of the tube may be placed in the heart area, in the abdomen, or in some other body compartment. The most common shunting procedure links the ventricle to the abdomen; it is referred to as a ventriculo-peritoneal shunt.

The shunt contains a one-way valve to prevent a reversal of flow. A properly operating shunt is highly successful in channeling away excess cerebrospinal fluid and preventing the buildup of pressure in the head. The recovery of brain shape and size can be quite dramatic: within 2 weeks of installation, special X-rays may show the brain to have returned to a nearly normal shape. Swinyard, *supra* note 9, at 17-18.

> arrest, he was not to be put on a respirator and no drugs were to be used.[15]

Nevertheless, Carlton managed to survive. Eventually, after a television investigation into denial of treatment at the hospital and children's shelter, he was given the lifesaving surgery he had been denied.

Bloomington, Indiana, Infant Doe Case

Probably more than any other single event, the Infant Doe case focused the attention of the Nation on denial of treatment to children born with disabilities. For one dramatic week in the spring of 1982, as the public followed the increasingly desperate efforts of the potential adoptive parents and the child's guardian *ad litem* to save his life, national newspapers wrote of the legal, ethical, and social ramifications of the withholding of lifesaving surgery, food, and water from a Bloomington, Indiana, baby.[16]

The child was born on April 9, 1982, with a tracheoesophageal fistula.[17] The most significant aspect of the condition is that the child cannot take nourishment normally. Left without surgery, a child will die. This condition, clearly life threatening, may be corrected by an operation that, performed early, has better than a 90 percent chance of success.[18] But Infant Doe differed from other children with a tracheoesophageal fistula because he also had Down syndrome, a congenital disability usually producing some degree of mental retardation.[19]

Although pediatricians called into the case recommended immediate transfer of Infant Doe to a hospital equipped to provide surgery,[20] the obstetrician who had delivered the child:

> insisted upon. . .pointing out to the parents that if this surgery were performed and if it were successful and the child survived, that this still would not be a normal child. That it would still be a mongoloid, a Down's syndrome child with all the problems that even the best of them have. That they did have another alternative which was to do nothing. In which case the child [would] probably live only a matter of several days and would die of pnuemonia probably. . . .Some of these children. . .are mere blobs.[21]

Based on what the obstetrician told them, the parents of Infant Doe agreed not to authorize surgery, food, or water for the child. But nurses at the hospital protested,[22] and the hospital agreed to place the matter before a court, while refusing to take any position on what course should be followed. A judge came to the hospital for a late evening session on Saturday, April 10, 1982. The hearing was not recorded,[23] and no guardian *ad litem* was appointed for the child.[24] The judge ruled

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[15] Paulus, *supra* note 8, at 325.

[16] *See, e.g.*, McCormick & Tribe, *Infant Doe: Where To Draw the Line*, Washington Post, July 27, 1982, at A15; *"Private" Death*, New York Times, Apr. 27, 1982, at A22; Will, *The Killing Will Not Stop*, Washington Post, Apr. 22, 1982, at A29.

[17] In about 1 of every 3,000 to 4,500 live births, the esophagus is incomplete, and the upper part of the esophagus is not connected to the lower part. This condition is called esophageal atresia. In about three-fourths of cases of such atresias, the incomplete esophagus (the tube connecting the mouth with the stomach) is linked to the trachea (windpipe). This latter condition is referred to as a tracheoesophageal fistula. Nelson, Textbook of Pediatrics 1041 (1979). It occurs in about 1 of 5,000 births. March of Dimes, *supra* note 14, at 3.
Atresia of the esophagus prevents food or liquids from getting to the child's stomach. A tracheoesophageal fistula can cause the aspiration of stomach juices if the lower part of the esophagus is joined to the trachea, and aspiration of food and liquids taken by mouth if the upper part of the esophagus is connected to the trachea. These conditions are somewhat more common in babies with Down syndrome than in other children. Each is lethal if untreated, and they are both considered surgical emergencies. Nelson, *supra*, at 1041.

[18] Bannon, *The Case of the Bloomington Baby*, Hum. Life Rev., Fall 1982, at 63, 67.

[19] Down syndrome is characterized by the presence of three instead of the normal two of the human chromosomes designated as number 21. Consequently, Down syndrome is also called Trisomy-21. It is characterized by a small flattened skull, flat nose, unusual slanting of the eyes, a protruding, furrowed tongue, a short, thick neck, short broad hands with small fingers that curve inward, short, wide feet with a gap between the first and second toes, short stature, sparse hair, low voice pitch, below-average muscle tone, a tendency to hearing impairments and respiratory disorders, and mental retardation. While persons with Down syndrome exhibit a combination of several of these characteristics, it is rare for any one individual to exhibit all of them. Mental development is usually retarded, generally in the moderate to severe range, although it is possible (albeit unusual) for an individual with Down syndrome to have average or even superior intelligence. R. Burgdorf, Jr., The Legal Rights of Handicapped Persons 39 (1980).

[20] *In re* Infant Doe, No. GU 8204–004A, slip op. at 2 (Monroe County Cir. Ct. Apr. 12, 1982), *petition for writ of mandamus and prohibition denied sub nom.* State *ex rel* Infant Doe v. Monroe Circuit Court, No. 482 S 140 (Ind. Apr. 14, 1982), *appeal dismissed sub nom. In re* Infant Doe, No. 1-782A 157 (Ind. Ct. App. Feb. 3, 1983), *cert. denied* 464 U.S. 961 (1983), *reprinted in* 2 Issues in L. & Med. 77, 78 (1986).

[21] Dr. Walter Owens, *quoted in* Petition for Writ of Cert. at 8-9, Infant Doe v. Bloomington Hosp., 464 U.S. 961 (1983).

[22] Horan & Balch, *Infant Doe and Baby Jane Doe: Medical Treatment and the Handicapped Newborn*, 52 Linacre Q. 45, 51 (1985).

[23] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 72-73 (vol. II) (1986) (testimony of John G. Baker, Monroe County Superior Court, Bloomington, Ind.).

[24] *In re* Infant Doe, No. GU 8204-004A, slip op. (Monroe County Cir. Ct. Apr. 12, 1982), *reprinted in* 2 Issues in L. & Med. 77, 79 (1986).

"that Mr. and Mrs. Doe, after having been fully informed of the opinions of two sets of physicians, have the right to choose a medically recommended course of treatment for their child in the present circumstances."[25] The judge later wrote: "It is a harsh view that no life is preferable to life, but the great weight of the medical testimony at the hearing I conducted was that even if the proposed surgery was successful, the possibility of a minimally adequate quality of life was nonexistent. The physicians in attendance supplied the medical judgment."[26] The Indiana Supreme Court refused to overturn the ruling, and the child died of pneumonia 6 days after birth while attorneys were en route to file a petition for review by the United States Supreme Court.[27]

Commission Approach

This is not the first report in which the United States Commission on Civil Rights has dealt with medical discrimination against people with disabilities.[28] In its 1983 report, *Accommodating the Spectrum of Individual Abilities,* the Commission wrote:

> Handicapped people. . .face discrimination in the availability and delivery of medical services. While occasional denials of routine medical care have been reported, a much more serious problem involves the apparent withholding of lifesaving medical treatment from individuals, frequently infants, solely because they are handicapped. Recently, widely publicized denials of medical treatment to handicapped infants have occurred in Indiana, Illinois, and California.[29]

On May 1, 1984, the Commission approved in concept a hearing to obtain testimony from the legal, medical, and academic communities, from representatives of civil rights organizations, including those advocating on behalf of people with disabilities, and from the general public on the subject of medical treatment accorded to or withheld from newborn children with disabilities, with a special focus on the applicability of section 504 of the Rehabilitation Act of 1973.[30] In preparation for the hearing, staff conducted a literature review, legal research, and interviews with experts. The hearing took place June 12–14, 1985, in Washington, D.C. Forty-three witnesses testified, including specialist physicians, representatives of medical organizations, parents who had been involved in treatment decisionmaking concerning their children born with disabilities, representatives of disability groups, ethicists, medical and other personnel involved in hospital ethics committees, hospital administrators and support personnel, and current and former staff of the executive and legislative branches of the Federal Government.

The Commission held a second hearing, also in Washington, D.C., on June 26–27, 1986. Testimony was received from attorneys and disability rights advocates assessing the then-recent U.S. Supreme Court decision limiting Federal investigations under section 504 of denial of treatment to children with disabilities,[31] from academicians and an investigative journalist on the extent of discrimination and pervasiveness of discriminatory attitudes, from physicians and a judge who had been involved in denial of treatment about the context and rationales for that denial, from people with disabilities about their perspectives on denial of treatment, and from an academician and a Federal official about the potential that exists for people with disabilities.

Following the hearings, staff conducted significant additional research and examined agency documents and data.

The Commission employed a distinguished group of consultants, drawn from a variety of fields and perspectives in the area of disability, to assist it in providing research leads and in reviewing drafts of this report. They included Gunnar Dybwad, emeritus professor of human development at the Heller School, Brandeis University, and visiting professor at the University of Syracuse; James Ellis, professor of law at the University of New Mexico; Frank Laski, chief counsel for the Public Interest Law Center of Philadelphia; Reed Martin, professor of law at the University of Texas-Austin; Marguerite Mikol, president of Sick Kids Need Protection (SKIP), the national organization of parents of technology-assisted children; Charles Rice, professor of law at Notre Dame University School of Law; H. Rutherford Turnbull, professor of law and special education at the University of Kansas; Colleen Wieck, executive director of the Minnesota Governor's Planning Council on Developmental Disabilities; and Robert Williams, deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens. The Commission also employed Thomas Nerney, president of the Disability Institute and currently executive director of the Autism Society of America, first as a consultant and later as an expert.

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[25] *Id.* at 3, 2 Issues in L. & Med. at 80.

[26] J. Baker, *June 8, 1982, Letter of Judge John Baker to Anonymous Person,* 2 Issues in L. & Med. 81, 82 (1986). *See* chap. 3 for an examination of the view that people with Down syndrome lack a minimally adequate quality of life.

[27] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 204–05 (vol. II) (1986) (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.).

[28] When referring to disabilities or to people with disabilities throughout this report, except in quotations or when making direct reference to legal or medical terminology, the Commission has sought to use language defined as appropriate in the standards issued by the Research and Training Council Writing and Reporting About People with Disabilities (1986).

[29] U.S. Commission on Civil Rights, Accommodating the Spectrum of Individual Abilities 35 (1983).

[30] 29 U.S.C.A. §794 (West Supp. 1988).

[31] Bowen v. Am. Hosp. Ass'n, 476 U.S. 610 (1986).

In accordance with statutory[32] and regulatory[33] requirements, draft portions of the report which the Commission determined tended to defame, degrade, or incriminate persons or institutions were provided to them for comment. Verified answers received in response are reprinted as appendix D to this report. Commission policy also requires that relevant portions of its draft reports be provided to affected agencies for comment. Thus, relevant sections of this report were provided to State child protective services agencies; to the U.S. Department of Health and Human Services' Office of Human Development Services, Office for Civil Rights, and Office of Inspector General; and to the Civil Rights Division of the U.S. Department of Justice. Comments received from the Federal agencies are reprinted in appendix E to this report. Answers and comments were carefully reviewed and, when appropriate, modifications were made in the final report.

A Legacy of Discrimination

Treatment decisions resulting in the denial of lifesaving medical treatment to children with disabilities cannot be viewed in isolation. Together with discrimination in employment, barriers to access to transportation and physical facilities, and a tradition of institutionalization, these decisions may be viewed in the context of longstanding attitudes and practices toward people with disabilities.

Eight years ago, Judith E. Heumann, then deputy director of the Center for Independent Living in Berkeley, California, told the Commission:

> I belong to the largest civil rights group in the country. The statistics, while they vary, go anywhere from 35 million to 47 million and up, and yet our civil rights group still has not yet received the status within the nondisabled community as a civil rights group representing a body of oppressed people in this country who have thus far been unable to achieve our place within this society, based on the failure to provide appropriate services and probably most importantly based on the failure of people in this country to believe that disabled individuals are in fact people who have the ability to achieve and have the desire to achieve. I think it is still all too common that disabled people in this country are perceived of as people who are sick and who are in need of being taken care of, as opposed to people who have different needs and whose needs, in fact, can be met, which will allow us to achieve our goals.[34]

Historically, the notion that people with disabilities "are sick and. . .in need of being taken care of" has found outlet not only in paternalistic approaches that foster dependency but also in the view that such "sickness" imposes a burden too great to be borne either by the person with the disability or by society as a whole. As Frank Bowe, then director of the

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[32] 42 U.S.C.A. §1975a(e) (West Supp. 1988).

[33] 45 C.F.R. §702.18 (1987).

[34] U.S. Commission on Civil Rights, Civil Rights Issues of Handicapped Americans: Public Policy Implications 230, 230 (1980) (statement of Judith E. Heumann, Deputy Director, Center for Independent Living, Berkeley, California). The International Center for the Disabled estimates that in 1985 there were approximately 27 million individuals in the general population who were age 16 or older and had a disability. The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream iii (March 1986), conducted for ICD—International Center for the Disabled, in cooperation with the National Council on the Handicapped, by Louis Harris and Associates, Inc. The U.S. Department of Education estimates that, in 1986–87, "4,421,601 children with handicaps from birth to age 21 were served" by the special education system. U.S. Department of Education, Tenth Annual Report to Congress on the Implementation of The Education of the Handicapped Act 3 (1988).
In line with Ms. Huemann's testimony quoted above, in 1983 the Commission stated:

> Structuring society's tasks and activities on the basis of assumptions about the normal ways of doing things reflects the idea that there are "normal" people who can participate and there are people with physical and mental handicaps who cannot. When people are classified as either handicapped or normal, the only questions are who falls into which category and what criteria are used. A close examination of this handicapped-normal dichotomy, however, reveals fundamental flaws: it ignores the fact that abilities occur as spectrums, not as all-or-nothing categories, and discounts the importance of social context. The resulting distortion of reality is the wellspring of handicap discrimination.

U.S. Commission on Civil Rights, Accommodating the Spectrum of Individual Abilities 93–94 (1983). That is not to say that there is not a standard against which the health of individuals is measured. Rather, the point to be made is that categorizing persons based upon disabilities raises the very legitimate concern that it not obscure the extent to which such persons may in other respects have greater abilities than persons not in that category.

American Coalition of Citizens with Disabilities, told the Commission in 1980:

> Within the Colonies, and later the States, community mores recognized indolence as a prime evil. Because popular perceptions equated disability with inability, existence of a disability appeared reason enough to deny a person the right to participate in societal life.[35]

In the late 19th and early 20th centuries, acceptance of the purported science of eugenics resulted in the view that people with disabilities were a burden to be regarded as a menace. The American Coalition of Citizens with Disabilities has summarized this history in a brief submitted to the United States Supreme Court:[36]

> Th[e] stark history is. . .of the regime of segregation and degradation which by force of state statute deemed retarded people to be "unfit for citizenship."[37] In every state in inexorable fashion handicapped persons were legislatively declared a "menace to the happiness. . .of the community,"[38] "unfitted for companionship with other children,"[39] a "blight on mankind"[40] whose very "presence"[41] in the community was "detrimental to normal" people.[42]
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> Official policy was to "purge society"[43] of these "anti-social beings,"[44] to "segregate [them] from the world,"[45] so that they "not. . .be returned to society"[46] since a "defect. . .wounds our citizenry a thousand times more than any plague."[47] Disabled persons simply did not have the "rights and liberties of normal people."[48] The District of Columbia Board of Charity urged Congress, and it agreed, to authorize putting handicapped people away since they were "not much above the animal."[49] Handicapped people were "not far removed from the brute,"[50] not quite persons, but "by-products of unfinished humanity"[51] who were to be segregated for the benefit "of society,"[52] "to relieve society of the 'heavy economic and moral losses arising from the existence at large of these unfortunate persons.'"[53] It was important to find a "way of getting rid of these kinds of cases."[54] Government reports labeled handicapped people "a parasitic predatory class,"[55] a "danger to the race,"[56] "a blight and a misfortune both to themselves and to the public"[57] whose role "in discounting social progress is by far the most potent influence for evil under which society is struggling today."[58]

As Justice Thurgood Marshall noted:

> Fueled by the rising tide of Social Darwinism, the "science" of eugenics, and the extreme xenophobia of those years, leading medical authorities and others began to portray the "feebleminded" as a "menace to society and civilization. . .responsible in large degree for many, if not all, of our social problems."[59]

Attitudes toward individuals with a disability were harsh. One article in the Massachusetts Medical Society magazine in 1912 stated that "[t]he social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are a parasitic, predatory class, never capable of self support or of managing their own affairs."[60] A Chicago ordinance provided that no person "who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person" could be found "in or on the public ways or other public places," and that no such person could "expose himself to public view."[61]

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[35] F. Bowe, *An Overview Paper on Civil Rights Issues of Handicapped Americans: Public Policy Implications*, in U.S. Commission on Civil Rights, Civil Rights Issues of Handicapped Americans: Public Policy Implications 7, 9 (1980).

[36] Amicus Curiae brief for the American Coalition of Citizens with Disabilities, Bowen v. Am. Hosp. Ass'n, 476 U.S. 610 (1986). The text of footnotes 37 through 58 are reprinted as they appeared in the brief.

[37] 1920 Miss. Laws 294, ch. 210, §17.

[38] 1919 Ala. Acts 739, No. 568, §7.

[39] 1909 Wash. Laws 260, tit. I, subch. 6, §2.

[40] Report of the Vermont School for the Feeble-Minded 17-18 (1916).

[41] Report of the Rhode Island School for the Feeble-Minded 21 (1910).

[42] California Board of Charities and Corrections, First Biennial Report 41 (1905).

[43] Wisconsin Board of Control, Biennial Report 321 (1898).

[44] Report of the Commission on Segregation, Care and Treatment of Feeble-Minded and Epileptic Persons in Pennsylvania 43 (1913).

[45] Thirty-Sixth Annual Report of the Indiana School for Feeble-Minded Youth 14 (1914).

[46] First Biennial Report of the Board of Commissioners of Nebraska Institutions 10 (1915).

[47] Fourth Biennial Report of the Board of Trustees of the Utah State Training School 3 (1938).

[48] Fourth Biennial Report of the South Dakota Commission for Segregation and Control of the Feeble-Minded 3 (1932).

[49] *District of Columbia Appropriations Bills: Hearings Before the Comm. on Appropriations*, 67th Cong., 2d Sess. 96 (Jan. 13, 15, 1932).

[50] Mental Defectives in Virginia: Special Report of the Board of Charities and Corrections to the General Assembly of 2926, at 20.

[51] Baldwin, *The Causes, Prevention and Care of Feeble-Minded Children*, in Proceedings of the Texas Conference of Charities and Corrections at Its Second Annual Meeting 87 (1912).

[52] *See, e.g.*, 1919 Ga. Laws 379, No. 373, §3.

[53] 1915 Tex. Gen. Laws 143, ch. 90, §§1,2.

[54] *Connecticut School for Imbeciles: Hearings on H.B. No. 644 Before the Joint Standing Committee on Humane Institutions* 20 (typed transcript, Feb. 25, 1915) (statement of Mr. Kerner of Waterbury).

[55] Report of the Vermont School for Feeble-Minded Children 17-18 (1916).

[56] *Report of the Legislative Visiting Committee*, Wisc. Sen. J. 263 (48th Leg. Sess.).

[57] Thirteenth Biennial Report of the Kansas School for Feeble-Minded Youth 12 (1906).

[58] Mental Defectives in Indiana: Third Report of the Committee on Mental Defectives 6 (1922).

[59] City of Cleburne v. Cleburne Living Center, 473 U.S. 432, 461-62 (1985) (Marshall, J., concurring) *(quoting* H. Goddard, *The Possibilities of Research as Applied to the Prevention of Feeblemindedness*, in Proceedings of the National Conference of Charities and Correction 307 (1915)).

In *Heredity and Human Progress*, a physician advocated that children with severe disabilities, including "idiots," most "imbeciles," and "epileptics" should be eliminated for the safety of the Nation through the use of a painless gas.[62]

In 1941 a physician addressing a luncheon during the annual meeting of the American Psychiatric Association said: "[W]e have too many feebleminded people among us. . . .The idiot and the imbecile seem to me unresponsive to the care put upon them. They are not capable of being educated; nor can such defective products ever be made to be so."[63] He spoke "in favor of euthanasia for those hopeless ones who should never have been born—Nature's mistakes," urging that when a "competent medical board. . .acting. . .on the application of the guardians of the child, and after three examinations of a defective who has reached the age of five or more, should decide that that defective has no future nor hope of one. . .it is a merciful and kindly thing to relieve that defective—often tortured and convulsed, grotesque and absurd, useless and foolish, and entirely undesirable—of the agony of living."[64] An editorial in the issue of the *American Journal of Psychiatry* that published the physician's address suggested that the attitude of parents who opposed elimination of their "idiot" children was a fit subject for psychiatric analysis and correction:

> It is difficult to conceive how normal affection can be felt for a creature incapable of the slightest response; and exaggerated sentimentality or forced devotion which can serve no possible purpose can hardly be looked upon as desirable. . . .
>
> . . . .
>
> [T]he psychiatric problem. . .[of] the "fondness" of the parents of an idiot and their "want" that he should be kept alive. . .we believe deserves study—the extent to which it exists, in fact and not merely as a generalization of opinion, what underlying factors. . .are discoverable, whether it can be assessed as healthy or morbid, and whether in the latter case it is modifiable by exposure to mental hygiene principles.[65]

Although contemporary justifications for denial of treatment to children with disabilities are typically less harshly worded, a clear continuity of thought can often be found. Contemporary bioethicist Peter Singer writes:

> When the death of a defective infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the defective infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second.[66]

A noted authority on child abuse and neglect argues that the state should intervene to save the life of a child only when the child would have a "life worth living or a life of relatively normal healthy growth."[67]

The complex and difficult questions surrounding treatment decisionmaking for children with disabilities must be approached with sensitivity to the effects of this background of dehumanizing attitudes concerning people with disabilities. Dehumanizing stereotypes are common to virtually every form of discrimination, including that based on disability.[68]

This report thus begins with an examination of the context of such decisionmaking in a chapter that explores the parent-physician relationship and the sort of information about disability sometimes provided parents by physicians. The next chapters consider what the evidence suggests about the potential quality of life of people with disabilities in contrast to what are often inaccurate assumptions about their quality of life. The report then describes in detail the history and current status of legal standards governing medical treatment for those with disabilities. The degree to which these standards are being implemented and the performance of governmental and nongovernmental institutions in enforcing them are assessed. The report ends with findings of fact and recommendations for the future.

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[60] A.M. Clark and A.D.B. Clarke, eds., Mental Deficiency: The Changing Outlook, 16–17, *quoted in* Evans, The Lives of Mentally Retarded People 43 (1983).

[61] Formerly Chicago, Ill., Mun. Cod. §36–34 (1966).

[62] D. McKim, *Heredity and Human Progress* 189, 193 (1900).

[63] Kennedy, *The Problem of Social Control of the Congenital Defective*, 49 Am. J. Psychiatry 13, 13 (1942).

[64] *Id.* at 14.

[65] *Euthanasia*, 99 Am. J. Psychiatry 141, 143 (1942).

[66] Peter Singer, Practical Ethics 134 (1979).

[67] J. Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 Yale L.J. 645, 651 (1977).

[68] *See generally* U.S. Commission on Civil Rights, Accommodating the Spectrum of Individual Abilities 22 (1983).

Chapter 2

The Physician-Parent Relationship and Treatment/Nontreatment Decisionmaking

Much of the popular and scholarly debate over the question of denying treatment to children with disabilities assumes a conflict between the rights of parents to make a choice concerning medical treatment for their child and whatever rights the child may have to lifesaving treatment despite the views of the parents. However, testimony before the Commission suggests that this is an artificial conflict, because it is normally inaccurate to assume that it is solely the parents of newborn children who actually decide whether to provide or withhold lifesaving medical treatment. In the words of Dr. Rosalyn Benjamin Darling: "In the decisionmaking situation, parents are likely to feel confused when confronted with a disability about which they know little. As a result, they rely heavily on the information and attitudes communicated to them by the physician. In most cases, the parents' decision reflects the physician's decision."[1]

One Commissioner summarized the evidence heard by the Commission:

> To the parents who testified, it was clear. . .that most parents are indeed influenced primarily by the recommendations of their physicians and that those recommendations can be and sometimes are based on a totally erroneous view of the child's abilities and future quality of life.[2]

Factors that Impair Independence in Parental Decisionmaking

It is important to understand the situation in which most parents suddenly confronted with a child with a disability find themselves. Assistant Secretary Madeleine Will pointed out:

> A parent may have had no experience with a person with a disability, and suddenly, at a moment's notice, finds himself or herself at an existential cliff, and one is very much dependent on this physician who is in some way going to protect you, one imagines, from a cataclysm, and one is dependent on the quality of information that he or she provides.[3]

The period surrounding birth is one of considerable stress and emotion, and for nondisabled parents, the birth of a child with a disability typically comes as a great shock. It frequently produces feelings of depression, grief, anger, and guilt. Because most new parents of a child with a disability have had little or no interaction with people who have disabilities, their reactions are often dominated by the stigmatization of people with disabilities to which they have been pervasively and sometimes subconsciously subjected for most of their lives. This stigmatization may produce in their minds a picture of the child's condition and prognosis that has little basis in fact. The Spina Bifida Association of America (SBAA) emphasized the problems:

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[1] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 181–82 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc). *Accord id.* at 41–42 (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas) ("I dispute the predicate. . .that parents make the decision. I think that kind of aseptic view runs contrary to the published literature in the health field and it also runs contrary to some of what I have been told by physicians who are neonatologists, pediatric surgeons, and pediatricians.").

[2] *Id.* at 5 (opening statement by Commissioner Robert A. Destro).

[3] *Id.* at 92 (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education).

Parents of a newborn spina bifida child are expected to make rational life and death decisions when what was expected to be a joyous time has instead become an occasion for confronting the concerns of the unknown. The decisions must be made quickly and under great stress. Dr. Rosalyn Darling, a member of SBAA's Professional Advisory Committee, has written that decisions are often made by physicians and individuals who have very little contact with the disabled community; consequently, decisions concerning treatment are often "stacked" against the newborn with a problem.[4]

Because the parents typically lack knowledge and are in such a state of stress, they turn for information and recommendations to the physicians caring for their child. Medical sociologist Rosalyn Benjamin Darling has done several studies of the relationship between the physicians and parents of children with disabilities. She noted:

> [P]arents are very vulnerable immediately after having given birth to a handicapped child. The hospital is not their natural habitat, and the medical milieu is frightening to them. They know very little about birth defects in general and their child's defect in particular. They turn readily to the "experts" who can help them understand what is happening to them. They have learned to trust physicians and to respect their opinions. Not surprisingly, they often defer to the physician's expertise in deciding whether their child is to be medically or surgically treated—or allowed to die.[5]

Evan Kemp, a lawyer with a disability who directs the Disability Rights Center, made a similar point:

> I think that at time of birth, when parents are very distraught, when they find that they don't have a child that measures up to the children of their friends, they're very impressionable at that time and under a great deal of stress, and I think that doctors have tremendous power to influence them, and I think they do influence them. . . .[6]

Influence of Physicians

Dr. Anne Fletcher, a neonatologist at Children's Hospital National Medical Center, told the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

> [I]t is important, that we make a recommendation of what is to be done. That is not to say that we don't feel the parents have a decision to make, but it is a decision with us and not a decision on their own. And we usually have felt it is our duty to make a decision, and then have them agree with us, rather than to have them feel they made the decision completely on their own.[7]

Another physician, who specializes in the treatment of spina bifida, has written:

> Invariably, in these circumstances, families make a decision based on information that is given to them by the pediatrician, pediatric neurologist, or neurosurgeon. The great likelihood is that any one of these physicians will have his/her own philosophy concerning what should be done and, therefore, whether intentional or unintentional, the information will be skewed. It is, therefore, the physician that is responsible for the immediate decision for or against surgery.[8]

Do parents or physicians typically initiate discussion of denying lifesaving treatment? In his team's study of approximately 150 cases of denial of treatment, investigative journalist Carlton Sherwood testified:

> [N]ot one parent we interviewed—and we spoke with several dozen who were personally involved on both sides of the treatment issue—not one said they took any initiative in the decisionmaking process; invariably, it was the physician, often teams of physicians, who approached the parents and recommended, strongly and persistently sometimes, for a course of treatment or nontreatment.

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[4] *Quoted in* 49 Fed. Reg. 1649-50 (1984).

[5] Darling, *Deck Often Stacked Against Defective Newborns*, American Medical News, Jan. 14, 1983, at 23. *Cf.* the description in an anonymous letter from a parent submitted for the record by Dr. Walter Owens:

> [A]t delivery I just remember being shocked that I, as a young, healthy person who avoided all artificial ingredients during my pregnancy, ate sensibly, could have given birth to an infant with multiple deformities. I didn't know anything about spina bifida, its consequences for the baby or the family; I guess I must have looked very bewildered as to the correct choice to make regarding surgery for a shunt, etc. You told me that if it were your decision, you probably would not sign consent for surgery. You gave me a short, but complete description of what I could expect from surgery, quality of life. It was simply a presentation of facts. I decided against sustaining measures, the baby died in a short time. . . .

Anonymous letter to Dr. Walter Owens (Aug. 20, 1983) (available in files of U.S. Commission on Civil Rights).

[6] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 29 (1986) (vol. II) (testimony of Evan J. Kemp, Jr., Director, Disability Rights Center).

[7] Testimony of Dr. Anne Fletcher, Transcript, Sixteenth Meeting of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 17 (Jan. 9, 1982), *quoted in* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment 210-11 (1983).

[8] Epstein, *Meningomyelocele: "Pitfalls" in Early and Late Management*, 30 Clinical Neurosurgery 366, 366-67 (1982). *See generally* National Legal Center for the Medically Dependent and Disabled, The Medical Treatment Rights of Children with Disabilities §5.02 (J. Bopp ed. 1987).

> In all but a few cases, the parents said they went along with their physician's recommendations and would have followed the same doctor's advice had his recommendation been different.
>
> All, and I emphasize all, the doctors we spoke with confirmed this decisionmaking process.[9]

Professor Turnbull told the Commission, "[P]hysicians set the agenda. The person. . .who has the ability to set the agenda has to a large degree the ability to control the outcome."[10]

In an article in *Clinical Pediatrics,* Drs. Stephen Ragatz and Patricia Ellison wrote about their own case conferences with parents "during which they [the parents] were asked directly to give an indication of whether or not they concurred that support be withdrawn."[11] Coauthor Dr. Patricia Ellison, a pediatric neurologist in private practice in Denver who also holds an academic appointment, testified before the Commission. Asked whether her article suggested that "there was a preexisting opinion that support be withdrawn and that the parents were then asked whether they concurred or disagreed," Dr. Ellison said: "There was not a decision [in any of those cases] ever offered by the doctor that support be withdrawn. However, it should be clear that if the issue is being raised, this is a consideration in the doctor's mind as well. You are not going to hold conferences for those babies about whom this would not be an appropriate concern."[12] When she was asked whether it is usually the parents or the health care personnel who initiate the question of continuing lifesaving support, she testified that sometimes it comes from one and sometimes from the other, but that when it comes from the parents:

> [w]e try to respond to the questions and needs of the parents, but would never have held a conference where this issue of support would be set up in the sense of a decisionmaking process, unless we as physicians felt that this was an appropriate case to do that. We might meet with the parents and answer questions and say, "We understand your worries, but look, at this time, things seem to be. . .[going] this way and this is not a time for such a conference."[13]

Physicians with a bent toward denial of treatment can be quite insistent in conveying negative information, as they were with the parents of Baby Jane Doe: "During her five months in the intensive care nursery, Dan and Linda would see their baby smile and ask hopefully if she were making progress. No, the doctors would respond, she wasn't."[14]

> Physicians had urged Dan and Linda to place Keri-Lynn [Baby Jane Doe] in a home for the severely disabled shortly after birth. Instead, the parents took her home.

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[9] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 50 (1986) (vol. II) (testimony of Carlton Sherwood).

[10] *Id.* at 58 (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas).

[11] Ragatz & Ellison, *Decisions to Withdraw Life Support in the Neonatal Intensive Care Unit,* 22 Clinical Pediatrics 729, 732 (1983). The physicians wrote:

> We initially assumed that the decision to withdraw support was chiefly the [prerogative] of the physician, acting in accordance with the parents' wishes. Decisions were made after full discussion with the parents. We subsequently learned that parents considered that they had made such decisions, and we became more willing to let the parents make them, in infants who were considered eligible for such a decision by the physician. *On occasion,* quality of life issues were raised by the parents prior to discussion initiated by the physician.

Id. at 729–30 (citation omitted) (emphasis added).

[12] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 219–20 (1986) (vol. II) (testimony of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver). Appearing before the Commission, Dr. Ellison characterized as a "misrepresentation," *id.* at 219, the view "that there was a preexisting opinion that support be withdrawn and that the parents were then asked whether they concurred or disagreed," *id.* (question by Ms. Hanrahan). *Cf.* the language in another of her articles (Walwork & Ellison, *Follow-up of Families of Neonates in Whom Life Support Was Withdrawn,* 24 Clinical Pediatrics 14 (1985)):

> [F]amilies were told, during the decision-making conference, that the decision would be made by the physician with consideration of the families' wishes and thoughts. . . .

Id. at 16.

> We. . .found that the parents accepted the responsibility for the decision to withdraw support, even when the professional staff considered that the decision had been made by the professional staff, not by the parents.

Id. at 20.

In her testimony, Dr. Ellison said, "It should be also well-stated that with parents who felt that this was really something that was not in keeping with their concerns, none of the support was ever withdrawn from such a child. We would never have considered such a thing." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 220 (1986) (vol. II) (testimony of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver.)

[13] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 239 (1986) (vol. II) (testimony of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver). *Cf. id.* at 267 (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens) ("[O]ne wonders why parents with newborns with severe disabilities are even put in a position of having to make such decisions when they are clearly operating under so much stress. Physicians often serve to exacerbate an already highly charged and tense situation by presenting the parents of an infant with severe disabilities with life and death choices that they would never, ever consider presenting to parents of a nondisabled child.").

[14] *'Adorable' Baby Jane Doe Finally Is Home,* Milwaukee Sentinel, May 25, 1984, pt. 1, at 8, col. 1.

> "They said she'd only know pain and that she wouldn't recognize us," Linda said. "If we had placed her in a home, she would have been like they said. Now, she's out and doing things."[15]

Although parents may seek to do what they think is best for their children, their assessment of what is best depends on the information they have. Nondisabled parents who are suddenly confronted with the birth of a child with a disability are not likely to enter the decisionmaking process with a background of adequate and accurate information. Adrienne Asch, who teaches social psychology at the City College of New York, testified:

> [B]ecause parents of disabled children, and especially disabled newborns, rarely share this minority characteristic [of being a person with a disability],. . .they are in an extremely difficult position to advocate for that infant. The parents of other children with minority characteristics can do this much better. They know what life holds in store for that infant and their child. They can advocate against those who would hurt their children for those minority characteristics, because even though they may know that life is fraught with problems, it is also going to contain various joys.
>
> But the parents of a disabled infant, moments, days after its birth, have very little such information. In fact, they are likely to have been given information by physicians, by social workers, by any other professionals, by clergy, that reinforces whatever stereotypes they have about the limits and deficits and tragedy of so-called defective, deformed, damaged infants.[16]

There seems to be near unanimity, from health care personnel who support as well as those who oppose denial of treatment, that in all but a handful of cases the manner and content of the medical provider's presentation of the issue will be decisive in determining the parental "decision." One nurse has written:

> Whether and to what extent such children are treated can be influenced by physicians and nurses. Suppose, for example, the staff tells the parents, "It is possible to operate on your baby and close his back, but his legs will still be paralyzed and deformed. Most likely he will never have bowel or bladder control and will probably develop hydrocephalus, which may require many operations with possible complications. Or, we can do nothing and allow him to die." Would you be surprised if the parents opted for death?
>
> On the other hand, a positive attitude can go a long way in persuading parents to accept their baby. This has been the stance of our nursing staff. We encourage parents to touch, hold, feed, talk to, and play with their infant. We tell them to bring in music boxes, toys, and, later, even clothes. By focusing on the normal things the baby does, we foster a positive image of the child. For example, we might say, "Look how strongly he sucks" and "See how tightly she holds your finger." We try to emphasize that their baby does things all babies do.[17]

One of the lead physicians involved in the selective treatment program at Children's Hospital of Oklahoma,[18] Dr. Richard Gross, has said: "I think it takes a great deal of courage on the. . .[part] of parents to say, in the face of a recommendation from a physician, that they wish to go counter to that. They certainly do not have the background at the time the child is born to really know what is expected."[19] Dr. Mildred Stahlman was even more direct:

> I can persuade 99 percent of parents to my way of thinking if I really work at it, even if I am 100 percent wrong. If I tell them in such a way that I appear concerned and that I am knowledgeable and that I have their interest at heart and the interest of their. . .newborn baby, there is no question in my mind but that they will let me "cut off that infant's head."[20]

From a treatment perspective opposite to that of Dr. Gross, Dr. David McLone testified concerning his experience with parents of children with spina bifida:

> I have now treated about 300 newborns and had this midnight discussion with about 300 families, and I have not had one family, once fully informed of the availability and the likely outcome of treatment, who has refused to have the back repaired at the time of birth.
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> In my experience in the cases I am familiar with where the decision was made not to close the back, that decision, in essence, was made by the physician and by what he told

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[15] Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, Newsday, Dec. 7, 1987, at 2, 23.

[16] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 125-26 (1986) (vol. II) (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York). *See also id.* at 141 (testimony of Mary Jane Owen, Director, Disability Focus, Inc.) ("Unfortunately, handicapped infants are born into alien families, families that have already probably stated the only requirement they have of a child was that it must be perfect. . . .").

[17] Homer, *Selective Treatment*, 84 Am. J. Nursing 309, 309-10 (1984).

[18] See chap. 1 and text accompanying notes 7-15.

[19] *Take Two: Who Lives, Who Dies?—Part II* (Cable News Network, Feb. 22, 1984), (Radio-TV Monitoring Service, Inc., Transcript at 5).

[20] *Quoted in* Patrick, *Little Murders*, 10 New Times 32, 36 (1978).

> the family, and the family went along with the decision of the physician not to close the back.[31]

The same picture emerged from testimony elicited from those associated with health care consumers. The deputy director of the National Information Center for Handicapped Children and Youth, Patricia McGill Smith, described an instance in which parents of a child with spina bifida received a medical recommendation of no treatment based on that disability and "predictable mental retardation." They initially accepted this recommendation. "Her parents were loving, good people," Smith testified, "but they were operating on the directive of the doctor who said, why sustain the life of someone who will have two kinds of disabilities. . . .Those parents were given inaccurate information. . . ." As the leader of a parent-to-parent support group, Smith was called in to assist the parents. She provided them with more accurate information about the prognosis for their child and the support systems available for them, and in time the parents changed their mind. Today, the girl is alive, without a trace of mental retardation.[32]

Betsy Trombino, the parent of a child with orthopedic disabilities, has worked for 6 years in the field of parent support. She testified:

> We're asked to make decisions as to whether our children live or die, and, yet, all the information is coming from people saying, he'll never do this, he'll never do that, he's not ever going to go to school or walk or talk or even roll over, so why would you want him to live?[33]

Misinformation Among Medical Personnel

Special Education Professor Ruth Luckasson described the prevalence of misinformation among many health care personnel and the bioethicists who advise them:

> Regrettably, reports of the advances in special education, habilitation and rehabilitation have not yet received wide dissemination in either the popular media or the literature of other professions. . . .[O]ur review of the medical literature and the literature of the new bioethicists revealed that typical physicians and bioethicists have little or no familiarity with life possibilities or community resources available to individuals who are born with handicaps.
>
> Parents, who typically receive the information on the life prospects of their disabled son or daughter from their physician, cannot uniformly expect information free of false stereotypes and archaic prejudices. To the extent that parents rely on such misinformation as they make life and death decisions about their sons and daughters, their children's vulnerability to discriminatory treatment is aggravated.[34]

Surgeon General Koop testified:

> [I]t's very difficult for somebody to know, for example, as a pediatrician who sees only one or two of these in a lifetime, if that, just how other parents have done innovative and creative things, have rallied community support, have established organizations that are anatomically designed for that particular defect; and therefore, he tends to be a little less enthusiastic about what can be done than if he had all of this information at his hands.[35]

Dr. McLone took a similar position:

> The problem that I have noted and have been involved in with the decisionmaking process has been primarily ignorance on the part of the physician who is first confronted with the child, who then misinforms the family, and based on inappropriate information, the family usually makes, in my opinion, the right decision based on that information. However, the information they have been given is so inconsistent and out of line with what most major centers in the United States are experiencing at this time that the child is denied care based on misinformation.[36]

Inaccurate stereotypes are quite pervasive; so much so, indeed, that five members of the Supreme Court have characterized the history of mistreatment of people with mental disabilities as "grotesque."[37]

Weight of Parental Decisions

In light of this background, Professor Ellis testified that frequently the parental agreement to forego lifesaving treatment for their newborn child with a disability is not legally adequate to constitute informed consent:

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[31] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 19 (1985) (vol. I) (testimony of Dr. David McLone, Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

[32] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 254–55 (1986) (vol. II) (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).

[33] *Id.* at 263–64 (testimony of Betsy Trombino).

[34] *Id.* at 97 (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico).

[35] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 12 (1985) (vol. I) (testimony of C. Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

[36] *Id.* at 7 (testimony of Dr. David McLone, Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

[37] City of Cleburne v. Cleburne Living Center, 473 U.S. 432, 454 (1985) (Stevens, J. & Burger, C.J., concurring), and *id.* at 461 (Marshall, Brennan & Blackmun, JJ., concurring in part and dissenting in part).

> The law of informed consent. . .provides some guidance,. . .because legally adequate consent requires that the individual. . .have a sufficient amount of information to make a legally adequate judgment and that it be a voluntary judgment, that is, without undue influence by others.
>
> And both on voluntariness and particularly on the point of information, to suggest that the involvement of parents, who are often ratifying a judgment which they think. . .[was] made by a professional on the basis of current knowledge that may not indeed be without prejudice, looking to the kinds of requirements in consent law may suggest to us that it is inadequate to essentially launder discriminatory decisions by saying, "Yes, well the parent acquiesced in them" when their consent may not meet those tests.[28]

Other reservations have been expressed about taking parental denial of treatment decisions at face value. Sociology Professor Irving Zola testified that research suggests that miscommunication as well as misinformation lies behind many of them:

> [W]ith the few studies that have come out, when we try to study what the doctor thinks he said and what the patient thinks he or she heard in the situation, the discrepancies are so enormous that one might go so far as to say that any doctor-patient encounter should have a mediator or somebody else there that could help both parties communicate with each other.[29]

Carlton Sherwood's investigations substantiate concerns about the definitive nature of many parents' acquiescence in nontreatment decisions.

> [W]hen death was being discussed, parents were rarely, if ever, told exactly what method was planned. Euphemisms like "let nature take its course" cover everything from starvation to deliberate efforts to infect the newborns. One can only speculate what would happen if doctors were required to put their nontreatment recommendations in writing and spell out clearly for parents what it was they intended to do in their names, along with the consequences of such actions.[30]

Dr. Rosalyn Benjamin Darling testified:

> Even if we could legislate truly informed consent, however, we could never have certain knowledge about any child's future quality of life. Some of the parents who have the most negative attitudes in the immediate postpartum situation, learn to love their children dearly months, weeks, or even days later. Some children with the poorest medical prognosis shortly after birth develop into normal, healthy children. Very few cases are predictable with any degree of certainty. Treatment in most cases, therefore, seems appropriate.[31]

Conclusion

The evidence is strong that in many instances in which lifesaving treatment is denied to children with disabilities, those decisions are often influenced by what physicians tell parents. In practice, doctors are often the prime movers in denying the treatment.

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[28] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 30 (1986) (vol. II) (testimony of Prof. James W. Ellis, School of Law, University of New Mexico).

[29] *Id.* at 200 (testimony of Prof. Irving Kenneth Zola, Department of Sociology, Brandeis University).

[30] *Id.* at 50 (testimony of Carlton Sherwood).

[31] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 182 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

Chapter 3

The Role of Quality of Life Assessments in Denial of Medical Treatment

One of the most common justifications given for denying treatment to children with disabilities is that there are circumstances in which it is in the children's best interests to spare them a life of unacceptably poor quality. In the words of Dr. Norman Fost, chairman of the Committee on Bioethics of the American Academy of Pediatrics:

> Profound handicap may be a compelling reason for allowing a patient to die. For example, consider the infant with a severe intracranial hemorrhage and respirator dependency who is profoundly brain damaged but not comatose. Ever-improving technology makes it possible to keep such patients alive for longer periods. Some live in intensive care units for years, or at home at enormous expense. The treatment clearly has medical benefit—it maintains respiratory functions and prevents the complications of respiratory arrest—yet it often seems to serve no interest of the patient, who cannot appreciate any of the joys of living.[1]

Impairment or Societal Attitudes?

The testimony presented to the Commission and its research suggest that, with few exceptions, people who themselves have disabilities reject this form of analysis. In a letter to the editor criticizing a columnist's support for denial of treatment to Baby Jane Doe because the child's life would be "barren of joy," Price Grisham wrote:

> When will people who are perfectly intelligent, clear-headed and well-educated stop assuming that one must be healthy, handsome and preferably wealthy to be human and happy? I am not healthy (I have cerebral palsy), not handsome and, as a GS-5 clerk, will probably never be wealthy.
>
> My childhood and. . .[adolescence] were spent in more than a decade of operations and therapy. Yet I am quite sane and quite firm when I state that I would not exchange my handicapped body for that of the most muscular Redskins player, for through it I have learned more in the 30 years of my life than some people learn in a century.[2]

Typical of the views of many people with disabilities is this editorial from a leading disability rights movement newspaper, *The Disability Rag:*

> The issue is that everyone agrees that life as a disabled person is most probably a fate worse than death. . . .That's the accepted fact. Many of us, in fact, don't accept it at all. . . .
>
> . . . .
>
> Who stops to figure out *why* being disabled is such a horrible fate? Most disabled people (we can assume we're the experts in this) will tell you that, despite what everyone thinks, the disability itself is not what makes everything difficult. What causes the difficulty are the attitudes society has about being disabled: attitudes that make a disabled person embarrassed, insecure, uncomfortable, dependent. And the physical environment.
>
> The physical environment that keeps on being designed. . . .[w]ith no thought ever routinely given to designing things everybody can simply use. . . .
>
> Of course disabled people rarely can talk of quality of life. But it has precious little to do with deformity, and a great deal to do with society's own defects.

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[1] Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 Critical Care Clinics 149, 153 (1986).

[2] Grisham, *Baby Doe*, Washington Post, Dec. 11, 1983, at C6. *See also Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 272 (1986) (vol. II) (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens) ("Society places too much emphasis on the perception of quality of life, perceived value, intelligence and physical agility. Traditionally, persons with severe disabilities have not been consulted on those issues which have affected them most. I think my life has been worth living; I'm confident my family and those I care for feel the same way.").

> This said, we can get back to talking about the newborn infant with a deformity. Now we can ask why those parents would be happier seeing it dead. Today, that child means much expense, confinement to home, special schools, special transportation, life in an institution. The public talks about that kind of a life as though it is simply inevitable for deformed infants. What they should be asking is "why is it inevitable?"
>
> The issue is rights, but the issue is not the right to die. It is the right to live in a society that wants you. And it's easier for our society to get rid of these kinds of people right at the start than to deal with *why* life is so horrible for these people. Our society is what makes it horrible. We have the power to change that.[3]

When Dr. Walter Owens, the physician who delivered Bloomington's Infant Doe, appeared before the Commission, he read a letter from a couple who had written in support of the decision to let a child with Down syndrome die. The letter focused far more on the societal reaction that made life difficult than on impairments inherent in the disability itself. These parents wrote that they regretted choosing life-saving surgery for their child's esophageal atresia: "My husband and I chose life and got a hellish existence instead."[4]

That view was based almost entirely on the lack of acceptance their son encountered. After referring briefly to health problems such as "respiratory infections[,]. . .severe allergies accompanied by congestion, fatigue, irritability, sinus, and ear infections," the couple stated:

> The real trouble started for Charles when he became old enough to play outside. Although there were some instances of cruelty to our Down's child, the main expression to him by neighborhood children has been to ignore him. For seven years, Charles was a bystander who was permitted to sit on the side and watch their ball games. As a result of this experience, our son became a nonperson. His self-image plummeted, and one day he began to stutter. At first barely perceptible, the stuttering increased to a very severe level.[5]

The parents went on to tell how they eventually sent Charles away to a special residential school where he is "now protected from the 'kindness' of society."[6] Looking toward the future, they asked, "Will there be a group home and some sort of semi-independent living arrangement for Charles or will our son be reduced to the subhuman institutional existence presently endured by the majority of retarded citizens?"[7]

To accept a projected negative quality of life for a child with a disability based on the difficulties society will cause the child, rather than tackling the difficulties themselves, is unacceptable. The Commission emphatically rejects the view that an acceptable answer to discrimination and prejudice is to grant the "right to die" to those against whom the discrimination and prejudice exists. It is not tolerable to choose death for children with disabilities as the societal response to unjust treatment of people with disabilities.

As Robert Williams, now deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens, who himself has a physical disability and uses communication aids, testified:

> The way to secure commitments [to improve the way people with disabilities are treated and the services they receive]. . .is not. . .[to] suggest that care be withheld from newborn infants with severe disabilities until an adequate funding is provided to help them obtain their maximum developmental potential. What benefit can result from this strategy? At best it can be seen as an extreme example of circular reasoning. At worst it can lead to the most vicious of circles. Appropriate support services necessary to assist the families of newborns with severe disabilities to love and care for their child in their own home will not be available as long as we devalue the life of a child so much that it becomes acceptable to withhold the most ordinary care.[8]

Even when a negative conclusion about the quality of life of a person with a disability is not so self-consciously grounded in projections about the behavior of others, as in Dr. Owen's example, it may nevertheless be based on a view of disability colored by societal assumptions and expectations. Professor Harlan Hahn explains:

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[3] *Killing Babies: Left and Right*, The Disability Rag, May 1983, at 2, 6, © 1983 by The Advocado Press, Inc. Reprinted with permission. This view is consistent with Harlan Hahn's description of a "*sociopolitical* understanding which regards disability as a product of the interaction between the individual and the environment. . . .Whereas the medical approach concentrates on inabilities affecting individual performance,. . .the sociopolitical perspective emphasizes the social environment and the importance of cultural expectations." Hahn, *Public Policy and Disabled Infants: A Sociopolitical Perspective*, 3 Issues in L. & Med. 3, 3–4 (1987) (emphasis in original).

[4] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 212 (1986) (vol. II) (testimony of Walter Owens, M.D.) (quoting anonymous letter).

[5] *Id.*

[6] *Id.* at 212–13.

[7] *Id.* at 213.

[8] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 272 (1986) (vol. II) (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens).

> If it is possible to characterize succinctly the prevalent popular understanding of disability,. . .the sentiment might be described by the phrase "personal misfortune." Disabled children and adults are commonly perceived as the "victims" of ill fortune or adversity which can only be "overcome" through extraordinary displays of personal courage and perseverance. The image is constantly reinforced in the mass media, not only by feature stories that depict the supposedly remarkable accomplishments of a specific disabled individual but also by telethons and other presentations that portray disabled persons as weak, pathetic, and helpless. For the nondisabled majority, there are apparently only two kinds of people with disabilities: the overachievers, who gain acceptance by performing superhuman feats, and the despondent, who are doomed to an unthinkable fate.
>
> . . .Little thought is given to the possibility of modifying the environment or of developing policies to enhance the status of disabled persons. . . .[9]

In short, decisions purportedly—and often sincerely—made on the basis of the "best interests" of children with disabilities are all too frequently tainted by what the Supreme Court has characterized in the context of housing discrimination against people with mental disability as "irrational prejudice."[10]

Positive Quality of Life for Persons with Disabilities

The Commission received extensive testimony documenting the good lives that people with disabilities can have when barriers to their full integration are decreased, adequate access is established to education and employment, and pessimistic prognostications are not permitted to become self-fulfilling prophecies. Indeed, Professor Ruth Luckasson, who coordinates mental retardation programs at the University of New Mexico, stated:

> The lives of the infants born with disabilities or who acquire disabilities after birth have more potential now than at any other time in our history. Babies who receive nondiscriminatory medically indicated treatment can expect to become participating citizens leading rich lives as members of their community.[11]

Medical progress has been ongoing, making obsolete predictions based on past experience. Surgeon General C. Everett Koop testified: "My own lifetime has seen a complete reversal of success and failure. When I first began in the field of pediatric surgery in 1946, most of the things that now have a 95 percent survival had a 95 percent mortality, and indeed, some carried a 100 percent mortality."[12]

Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services at the Department of Education, described the striking progress seen in recent decades.

> Twenty years ago, the opportunities available to a severely impaired young adult might well have been meager. . . .Today, as a result of the opportunities offered by the Education of the Handicapped Act and the Rehabilitation Act of 1973 and the technological advances that are in no small part related to these landmark pieces of legislation, the possibilities are limitless.
>
> . . . .
>
> For over a decade, infants with severe impairments associated with Down's syndrome and spina bifida have been placed in programs within weeks after birth. In States where services are mandated at birth, educators and therapists provide instruction within the child's home on a regular basis. In many instances, before they reach the age of 3, children are enrolled in preschool programs, often with nonhandicapped children as classmates.[13]

As Ed Roberts, president of the World Institute on Disability and former director of the California Department of Rehabilitation, put it, "At first we thought people couldn't learn, but then we recognized we didn't know how to teach. Now we've learned how to teach people."[14]

Approximately 4.2 million children are now in special education programs nationwide. Particularly impressive progress in maximizing the potential of children with congenital disabilities has come from the growing use of "early intervention," an approach in which preschool children are provided stimulation and education to develop their capacities. With the widespread success of these programs for children, focus is now being placed on the transition from education to employment, with particular attention to "supported employment," in which those with the most severe disabilities are given ongoing assistance in training and supervision while employed.[15]

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[9] Hahn, *supra* note 3, at 4–5.

[10] City of Cleburne v. Cleburne Living Center, 473 U.S. 432, 450 (1985).

[11] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 95 (1986) (vol. II) (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico).

[12] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 7–8 (1985) (vol. I) (testimony of C. Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

[13] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 84–85 (1986) (vol. II) (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education).

[14] *Id.* at 106 (testimony of Ed Roberts, President, World Institute on Disability).

Advances in education have been paralleled by an increase in support groups for parents of children with disabilities. The deputy director of the National Information Center for Handicapped Children and Youth testified:

> There are better and more available parent-to-parent advocate support services today than there were 10 years ago. That doesn't mean that there are all the supports needed to sustain the help that families need, but as far as parent-to-parent supportive services, at the time when a child is born, there are people who are trained and who are willing to go in and help those families, and I would say I could find someone for every major medical center in this country that could do that. . . .[P]arent advocacy. . .is available and there are people who, if they have to make long distance calls or make a trip, will go and help parents when they find out they have this need. And indeed there are many systems in place to help the medical community, the legal community, the nursing staffs, to know how to get that help in.[16]

Also contributing to improvements in the last 20 years has been progress in rehabilitation technology, such as power wheelchairs and machines that assist people with vocal impairments to speak.[17] Ed Roberts emphasized another critical aspect in the achievement of potential: motivation to attempt and to innovate.

> I was told for years by the doctors I couldn't have a power chair; in fact, it was impossible, I didn't have the kind of muscles. Well, I fell in love. . . .and it was ridiculously inconvenient to take my attendant everywhere with me, I just couldn't be alone. Well I learned how to drive a power chair in 2 days. . . .
>
> I think sometimes. . .we forget. . .that people can do incredible things despite the prejudices, despite the dire predictions, if we give them the help they need. In this case, all I needed was something to adapt the wheelchair for me, to turn the controller around; it didn't cost anything really, and I probably saved the State thousands of dollars in people pushing me around to my classes and to other places.[18]

Repeatedly, those who support denying lifesaving treatment to children with severe disabilities invoke the horrors of institutionalization.[19] However, Special Education Professor Ruth Luckasson informed the Commission:

> Research such as that conducted in the case of the deinstitutionalization of all of the residents of Pennhurst State School indicates that handicapped people, irrespective of the severity of their disability, can live in the community. The fact that they don't is a policy decision that has been made by this society, not a reflection of their functioning ability.[20]

Although there is considerable experience with the effectiveness of integrated community living policies in a variety of places across the country, the availability of services to assist in finding employment and educational rehabilitative services is still spotty, varying from State to State and sometimes from community to community.[21] This reality may partially account for the continuing view of many that the lives of people with severe disabilities remain hopeless.

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[15] *Id.* at 87–88 (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education). Professor Luckasson testified: "In my own community, essentially all handicapped children, regardless of the severity of their disability, are educated on regular school campuses, not on isolated campuses, and are integrated to the maximum extent appropriate with nonhandicapped children." *Id.* at 95 (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico).

[16] *Id.* at 256 (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).

[17] *Id.* at 108–09 (testimony of Ed Roberts, President, World Institute on Disability).

[18] *Id.*

[19] *See, e.g., supra* note 7 and accompanying text. *See also Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 269-70 (1986) (vol. II) (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens).

[20] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 96 (1986) (vol. II) (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico). *See also id.* at 98–99; and chap. 4.

[21] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 100–02 (1986) (vol. II) (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico). *See also id.* at 187–88 (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.) (describing difficulties for families of children with disabilities in securing adequate financial support, obtaining an appropriate education, and seeking respite care and support facilities, but noting, "These are not problems that are inherent in the disability. If we had sufficient support facilities in society, if there were enough resources out there, much of the burden would be removed from parents, and the quality of life of all concerned would be significantly increased. . . .").

Quality of Life and Down Syndrome

Advocates of denial of treatment have attacked the accuracy of the positive picture of the potential quality of life with disability that appears to predominate among disability experts and people with disabilities themselves. The physician who delivered Bloomington's Infant Doe, Dr. Walter Owens, criticized those who present optimistic scenarios for children with Down syndrome: "The one who is involved in such care has to be enthusiastic about it or he can't do it, but sometimes his enthusiasm is not tempered by sufficient realization of the broader aspects of what he is doing."[22]

Although Dr. Owens lacks formal training in habilitation or the diagnosis of future disability and although he performed no neurological testing on Infant Doe,[23] he did not hesitate to give the Indiana trial court this projection of the child's future:

> My testimony was to the effect that I had personally had contact of one sort or another with a considerable number of Down's children over a period of years, that some of these children were mere "blobs." They were incapable of doing anything, and I used that word. That others were. . .no more than moderately retarded, that this sounded benign enough until you realize what "moderate retardation" meant. It meant that these children, as they grew up, were unable to do the normal things that normal children can, that I made the statement in regard to this, that I had never known a Down's child who was gainfully employed outside a sheltered workshop. I have had to revise that since I heard of one Down's child, a young woman, who is washing dishes in a restaurant. That's the sole one I have been able to encounter. I have never known a Down's child able to live on its [sic] own. They require constant attention the rest of their lives.[24]

Dr. Owens also told the Commission that the "lifetime cost" of a child with Down syndrome would "almost surely be close to $1 million," and that "The great majority of Down's syndrome children, if they survive to adulthood, develop premature Alzheimer's disease, and the last part of their lives is spent in almost total dependency." He said such a child is "more prone to develop leukemia, which is usually fatal."[25]

Dr. Owens' conclusions are strikingly out of touch with the contemporary evidence on the capabilities of people with Down syndrome. One author has noted:

> Most early data on the development of children with Down syndrome had come from institutional populations where the lack of stimulation and even deprivation obviously lead to a decrement of cognitive development. Studies. . .generally found the child with Down syndrome who had been institutionalized soon after birth to be at a severely retarded level. Yet children who had been reared at home had a more advanced cognitive development, which lasted three years after their subsequent placement in institutions. Other studies have noted the majority of children reared at home to be functioning in at least the moderately retarded range.[26]

One study has shown that children with Down syndrome who participated in early intervention programs performed at consistently higher levels of cognitive and adaptive functioning than comparable children raised without the benefit of such programs, and that such benefits "provide a [stable] foundation for subsequent learning and development."[27] Children with this foundation can develop skills that might otherwise have been lost. They can learn to walk, eat, and have the social improvement that sustains the will to learn—all freeing them from the need for "constant attention."

Both anecdotal evidence and empirical studies confirm that the availability of appropriate education and training provides a sound basis for optimism regarding the life prospects of babies born with Down syndrome. Six studies in particular demonstrate that adolescents and adults with Down syndrome can acquire skills that advance their development of independence.

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[22] *Id.* at 210 (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.).

[23] *Id.* at 224.

[24] *Id.* at 224–25. Owens defined "normal" as having an IQ above 80, although he said some might place it at 70 or above. "[I]n any case, a child [is normal] who has intelligence that would enable him to function as an independent individual in our society, and whose physical handicaps are not so great that he cannot at least have some function. . . ." *Id.* at 225. Pediatric neurologist Dr. Patricia Ellison would set a lower level for the point below which consideration of denial of treatment is appropriate. Those with an IQ of 50 to 70, she testified, "by and large live independently, they hold jobs, they do not attain levels of education of many people present in this room, but they function in society." *Id.* at 226. In her view, in "decisionmaking processes, your first concern should be. . .[those in the] profoundly to severely retarded range. . . ." *Id.*

[25] *Id.* at 234–35.

[26] Schnell, *Psychomotor Development*, The Young Child With Down Syndrome 207, 209 (S. Pueschel ed. 1984) (footnotes omitted).

[27] Connolly, Morgan, & Russell, *Evaluation of Children with Down Syndrome Who Participated in an Early Intervention Program[:] Second Follow-up Study*, 64 Physical Therapy 1515 (1984). *See also* Dmitriev, *Cognition and the Acceleration and Maintenance of Developmental Gains Among Children With Down Syndrome: Longitudinal Data*, 11 Down's Syndrome 6 (1988); Hanson, *Early Intervention for Children With Down Syndrome*, in New Perspectives on Down Syndrome (S. Pueschel et al. eds. 1987).

In 1974 Menolascino studied the attainment of such adaptive and independent living skills as ambulation, feeding, dressing, toilet etiquette, and grooming among a population of 72 adults with Down syndrome with a mean age of 33.4 years. Even though these individuals learned their skills in a residential facility with little stimulation, 75 percent were able to "walk freely and unassisted," and 79 percent could feed themselves "completely and neatly without help. . . ." Sixty-four percent were able to undress well and dress partially, i.e., "needing only occasional or minor help." Finally, significant levels of grooming ability were demonstrated: 69 percent could wash and dry their faces; 56 percent could brush their teeth; 24 percent could comb, brush, and/or part their hair; and 39 percent could shower and dry themselves completely and adequately. Menolascino concluded that "[o]verall, the levels of functioning are inconsistent with the prevailing belief that Down's syndrome prevents one from performing self-care tasks."[28]

In another area, in 1973 Sidman and Cresson reported on an attempt to devise a method that would allow two men with Down syndrome, who were labeled severely retarded, to learn to read. Beginning with the assumption that most people learn to read by first learning to match spoken words with pictures, and then to match printed words with pictures, Sidman and Cresson postulated that, through faulty teaching, most children with mental retardation never learn the final, purely visual step in the reading comprehension process, even though they have the capability of doing so. They devised a method to address this problem. The two subjects in the study were initially unable to read the 20 words that Sidman and Cresson had chosen as their focus. Ten months later, however, after experimentation with the new method, the two men were able to read between 50 percent and 75 percent of the words with comprehension. The researchers concluded that "teaching procedures, rather than subjects' deficiencies, may have set the limiting conditions, even at this level of retardation."[29]

In 1979 Hobson and Duncan reported on a study in which a small group of adults with Down syndrome was taught to use sign language. All had lived in institutions for most of their lives, their mean IQ was 20.2, and they were labeled profoundly retarded. At the beginning of the study, four of the subjects were "nonverbal with little ability to gesture," three had "very limited vocal skills and gesturing abilities," and two could be understood, on occasion, only with great difficulty. After 66 weeks of focused instruction, they had learned the signs.[30]

A study reported by Buddenhagen in 1971 described an effort to promote vocalization in "institutionalized children with Down syndrome who were severely retarded and exhibited very maladaptive behaviors." Institution records indicated that Larea, an 18-year-old woman who participated in the study, could not talk and frequently kicked, bit, and struck other residents and institution aides, although she did have some self-help skills and could respond appropriately to some verbal stimuli. After 21 hours of training that used a combination of incentives and direct instruction, Larea had acquired a fairly sizable verbal repertoire. Furthermore, Larea's social behavior improved so dramatically that reports that had previously characterized her as stubborn and mercurial began to call her cooperative and polite.[31]

These investigations all show that individuals with Down syndrome can indeed learn to read, to communicate, and to interact positively with others, activities that contribute to the development of independence. They provide "positive impetus for further exploration of specific techniques"[32] that may be used, at ever earlier ages, to prepare people with Down syndrome for independent living.

Despite Dr. Owens' statement to the court that he had "never known a Down's child who was gainfully employed outside a sheltered workshop,"[33] even persons with severe disabilities can be "productive employees. . .[W]ith appropriate support and ongoing supervision, individuals who typically would be targeted for sheltered employment or day habilitation programs can become productive, earning employees in industry settings."[34] One long term study has shown that the employability of adults with mental retardation in competitive environments is much more a function of factors other than the mere fact that an individual has mental retardation. The two factors with the greatest effect on the length and quality of the employment of the person with mental retardation were the extent to which they were accurately matched to jobs maximizing their particular abilities, and the degree to which relevant, high-quality, onsite supervision was available. In situations in which both of these maximized, the mean length of employment was 19 months.[35] By contrast, the mean length of employment for nondisabled people performing similar jobs was 5 months.[36] The 167 individuals in the study earned $1,069,309 over a 6-year period and paid $245,941 in taxes.[37]

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[28] Putnam & Rynders, *Advancing the Development of Independence in Adults with Down Syndrome*, in Down Syndrome: Advances in Biomedicine and the Behavioral Sciences 468–69 (S. Pueschel & J. Rynders ed. 1982).

[29] *Id.* at 469–70.

[30] *Id.* at 471–72.

[31] *Id.* at 472–73.

[32] *Id.* at 473.

[33] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 225 (1986) (vol. II) (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.). Dr. Owens told the Commission that subsequent to his court testimony, "I have had to revise that since I heard of one Down's child, a young woman, who is washing dishes in a restaurant. That's the sole one I have been able to encounter." *Id.*

Other studies show the ability of people with mental retardation to learn employable vocational skills. One example is the work of Gold, reported in 1973. Gold taught a group of 64 moderately and severely retarded individuals (about 40 percent of whom had Down syndrome) how to assemble bicycle braking mechanisms. After their training, 63 of the 64 were able to assemble the braking mechanisms correctly in six of eight consecutive trials. A year later, 53 of the 64 put together a 24-piece training brake, exhibiting a high degree of skill retention. The individuals with Down syndrome performed comparably with the others.[38]

Anecdotes corroborate what empirical studies postulate about the actual employability of persons with mental retardation. JoAnne Putnam and John Rynders relate several such success stories in their essay, "Advancing the Development of Independence in Adults with Down Syndrome." In this work, they describe individuals with Down syndrome who all lead prosperous vocational lives. Kathy Hagarty, 19 years old in 1978, was the librarian at the St. Collette School for Mentally Retarded Children. Jacques Dumont, in his early twenties in 1977, ran the addressograph and mimeograph machines in his office, ran errands to the bank and post office, made the morning coffee, and was considered a trustworthy employee. At age 23, David Kaul was earning $2.90 an hour for maintenance work for the contact lens manufacturer Precision Cosmet, and also mowed lawns with a $2,400 tractor that he had bought with his own savings. On weekends, Kaul cleaned the local fire station on a volunteer basis. At 31 years old, Dave Stevenson in 1979 was a grounds maintenance worker with the Maryland National Park and Planning Commission, earning $3.04 per hour. Stevenson received training through the vocational training program at the Melwood Horticulture Center, Inc. When he enrolled there in 1967, he was considered the lowest functioning person in the program because he had scored below 35 on the Wechsler Adult Intelligence Scale, and he was lacking even in self-care skills. These factors make his later success as a paid employee all the more impressive.[39]

Informed of Dr. Owens' estimate that the lifetime cost of a child with Down syndrome would be close to a million dollars, Diane Crutcher, executive director of the National Down Syndrome Congress, wrote that "the lifetime cost of a person with Down syndrome will drop dramatically because they are now being raised in the community to live in the community as tax-payers and not tax-burdens."[40] Dr. Owens' estimate of the cost associated with a person with Down Syndrome is a function of his assumptions about the inability of such an individual to take care of or support himself or herself. Yet, early intervention programs now foster such ability.

It is important to recognize that Down syndrome, with the lessened mental capacity associated with it, does not mean "an inability to learn, but rather as a slowed rate of learning."[41] Early intervention provides the framework for developing additional skills. By themselves, these skills avoid the cost of continual assistance. But they also create the basis for participation in employment, through which many people with Down syndrome can support themselves.

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[34] Kiernan, *Opportunities and Options for Employment*, in The Young Person With Down Syndrome[:] Transition From Adolescence to Adulthood 155, 161–62 (S. Pueschel ed. 1988) (footnote omitted). *Cf.* Wehman et al., *Competitive Employment for Persons with Mental Retardation: A Follow-up Six Years Later*, 23 Mental Retardation 274 (1985) [hereinafter Wehman].

[35] Wehman, *supra* note 34, at 276–79.

[36] *Id.* at 279.

[37] *Id.*

[38] Putnam & Rynders, *supra* note 28, at 475.

[39] *Id.* at 474–75.

[40] Letter from Diane M. Crutcher, Executive Director, National Down Syndrome Congress, to U.S. Commission on Civil Rights (May 9, 1988).

[41] Edwards, *Living Options for Persons with Down Syndrome*, in New Perspectives on Down Syndrome 337, 340 (1987).

These studies and anecdotes demonstrate the positive and powerful effects that focused and appropriate training and education can have on the lives of people with Down syndrome. As such, they suggest that a proper response to the diagnosis of Down syndrome at birth is not fatalistic resignation, but the "exploration of specific techniques" capable of advancing the development of independence.[42]

The final ground advanced by Dr. Owens to defend denying lifesaving treatment to children with Down syndrome is his assertion that they are prone to leukemia and Alzheimer's disease. Although it is true that those with Down syndrome have a somewhat greater statistical likelihood of developing leukemia, that incidence is still only 1 in 60,000.[43] That lifetime risk is less than the annual risk each of us faces of death from accidental drowning or as a result of a fire.[44] Dr. Owens may have been influenced by early studies that gave what proved to be highly inflated estimates for the incidence of leukemia in children with Down syndrome.[45]

Dr. Owens' statement that a majority of persons with Down syndrome develop premature Alzheimer's disease is flawed as well. In the words of the executive director of the National Down Syndrome Congress: "[A]lthough there is early evidence of Alzheimer-like. . .[symptomatology] in the brains of many persons with Down syndrome around the age of 35 (via autopsy), the majority do not show clinical signs of the disease until their 50's to 60's (if at all). . . ."; i.e., at about the same age as people without Down syndrome begin to exhibit clinical symptoms of the affliction.[46]

Studies have indeed shown that the autopsies of brains of most persons with Down syndrome over the age of 35 evidence "laboratory traits" of Alzheimer's.[47] Therefore, "many neuropathologists have simply stated that all persons with Down syndrome develop Alzheimer disease with age."[48] Oliver and Holland state, "From the neuropathological literature the assumption arises that all elderly people with Down's Syndrome. . .would therefore be expected to have the clinical signs of dementia."[49]

But this is not the case. There is a lack of correspondence between the laboratory results and clinical observations of senility.[50]

Some older persons with Down syndrome are considered "as normal as their juniors and hardly ever exhibit the personality changes or psychological problems observed in Alzheimer disease."[51] In a study of individuals with Down syndrome over age 36 whose autopsies showed the neuropathology of Alzheimer disease, only about one-fourth were characterized as exhibiting dementia.[52]

Inaccurate Prognoses

A substantial body of evidence shows that time and time again predictions of a poor quality of life made at birth for a child with a disability are subsequently proved wrong.[53] Too many examples have been adduced to be dismissed as isolated instances.

One of the most highly publicized cases, that of Baby Jane Doe in New York, is a striking example. The case contained many elements typical of such sagas: the denial of surgery following her birth; the unsuccessful efforts of a private attorney—prompted by a whistle blower—to obtain a court order for surgery; and the unsuccessful efforts of the Department of Health and Human Services to gain access to her medical records.[54] Finally, throughout the controversy, the accounts of the future predicted for her—should she survive—were unremittingly bleak.

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[42] Putnam & Rynders, *supra* note 28, at 473.

[43] Letter from Diane M. Crutcher, Executive Director, Down Syndrome Congress, to U.S. Commission on Civil Rights (May 9, 1988).

[44] In 1982, 2.3 people drowned and 2.2 died as a result of accidents caused by fires and flames for every 100,000 people in the United States. U.S. Bureau of the Census, Statistical Abstract of the United States 1986, p. 77 (106th ed.) (table 120). The risk that a person with Down syndrome has of developing leukemia in an entire lifetime is equivalent to 1.7 in 100,000.

[45] "One factor that confused early researchers. . .was the large number of [infants] with Down syndrome who developed what was thought to be acute myelocytic leukemia and then underwent spontaneous remission." Later researchers "showed that [infants] with Down syndrome are more likely to develop a leukemoid reaction clinically and histologically resembling acute leukemia. This leukemoid reaction, however, undergoes spontaneous remission and therefore cannot be classified as leukemia. Furthermore, [infants] with this leukemoid reaction who die of other causes have no histologic signs of leukemia outside of the blood or bone marrow, which is in contrast to true neonatal leukemia. . . ." Sassaman, *Oncology*, in Down Syndrome[:] Advances in Biomedicine and the Behavior Sciences 237, 237 (S. Pueschel & J. Rynders eds. 1982).

[46] Letter from Diane M. Crutcher, Executive Director, National Down Syndrome Congress, to U.S. Commission on Civil Rights (May 9, 1988).

[47] Oliver & Holland, *Down's Syndrome and Alzheimer's Disease: A Review*, 16 Psychological Medicine 307, 307 (1980).

[48] Schweber, *Interrelation of Alzheimer Disease and Down Syndrome*, New Perspectives on Down Syndrome 135, 135 (1987).

[49] Oliver & Holland, *supra* note 47, at 318.

[50] Schweber, *supra* note 48, at 138. "[P]rimary care providers have long been aware that the majority of adults with Down syndrome live out their lives with no apparent changes in personality or behavior." *Id.* at 135.

[51] Pueschel, *Health Concerns in Persons With Down Syndrome*, New Perspectives on Down Syndrome 113, 127 (1987).

[52] Schweber, *supra* note 48, at 138.

[53] *See Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 180 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.) ("[Q]uality of life is not highly predictable even with the best information about a child's current situation. Often, quality of life is better than what early prognoses would suggest.").

The director of the American Academy of Pediatrics, Dr. Harry Jennison, said, "'Baby Jane Doe'. . .not only has spina bifida but fluid on the brain and an abnormally small brain. The baby is so severely deformed that there is nothing that can be done."[55] A *Los Angeles Times* editorial noted, "Doctors say that without surgery the girl may live up to two years; with it she could live until she is 20, but she would be severely retarded, epileptic and paralyzed from the waist down, as well as in constant pain."[56]

The *Washington Post* quoted the court testimony of pediatric neurologist Dr. George Newman: "[O]n the basis of the combination of malformations that are present in this child, she is not likely to ever achieve any meaningful interaction with her environment, nor ever achieve any interpersonal relationships. . . ."[57] Newman also testified, "It's unlikely that she is going to develop any cognitive skills" and would experience "nothing whatsoever" that he considered positive on the cognitive scale.[58]

The baby's parents described in an interview what they were told about the child's future by medical personnel—the information on the basis of which they decided against surgery:

> "We were told. . .that the part of the brain that controls much of our awareness was either missing or not entirely formed.
>
> We are not talking about a spina bifida child,. . .one who could perhaps walk someday with braces. . . .She will be an epileptic. Her condition for future life is to be bedridden, and she would not have use of her hands.
>
> We also know that as she grew older, she would always be an infant. She would never know love. And while she might feel sorrow and joy, her overall condition would be pain."[59]

Asking "Is it a Life?" bioethicist Arthur Caplan (then on the staff of the prestigious Hastings Center) wrote of Baby Jane Doe, "No one should be forced by the government, [or] civil libertarians. . .to live such a life, even briefly."[60]

Notwithstanding the legal efforts opposed to providing medical treatment for Baby Jane Doe, she is alive today.[61] Although the courts had upheld her parents' decision to withhold operations to install a shunt and to close her back, the parents had time to change their minds. A shunt was installed, her back healed, and she was taken home.[62] As she left the hospital, Dr. George Newman had not changed his prognosis: "She will still be severely retarded and, I still think, bedridden all the days of her life."[63]

When they took her home, her father commented to a reporter, "We're happy because she appears to be happy."[64] About a month later, a reporter described her as "smiling and cooing as her mother feeds her. . . .[S]he grasps a visitor's finger in a tiny fist. . . ."[65] Already she was using her "unusable" hands. In June 1986, when she was 2 years and 8 months old:

> Her. . .father said [she] likes to throw a ball to the family's golden retriever, cruise around in a walker and try to sing "Row, Row, Row Your Boat." He said he and his wife decided initially against surgery because it appeared she could die at any moment and they did not want to add to the baby's pain.
>
> "All of a sudden it turned around," he said. "From that moment on, we really saw her sense of fighting and sense to live and we were full steam ahead with what had to be done for her."[66]

In December 1987, when she was 4, a reporter wrote of her, "Keri-Lynn talks and laughs; she smiles and hugs and screams and plants kisses firmly on a stranger's cheek."[67] She was using a wheelchair and attending school.[68] "I'm thrilled as can be," her father said. "The fact that she's able to relate to us and her environment is amazing. Her mental awareness is fabulous now."[69] She was "learning to mix with her peers."[70] Of course, she still has spina bifida. She does not walk, and requires frequent catheterization; she has had to have surgery for a dislocated hip.[71] But, in the following description of Baby Jane Doe at 4, it is hard to recognize the pain-wracked, unaware, bedridden creature of her doctors' confident predictions:

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[54] See chap. 5, text accompanying notes 25–32; and chap. 6, text accompanying notes 89–107.

[55] *Pro and Con*[:] *Should Uncle Sam Protect Handicapped Babies?* U.S. News & World Report, Jan. 16, 1984, at 63, 64.

[56] *Indecent Zealotry,* Los Angeles Times, Nov. 16, 1983, pt. II, at 6.

[57] Barringer, *Meese Approved Intervention in Baby Case,* Washington Post, Nov. 16, 1983, at A16.

[58] Transcript at 47, 95–96, People *ex rel.* Washburn v. Stony Brook Hosp., No. 83-19910 (N.Y. Sup. Ct. Oct. 19, 1983).

[59] *Quoted in* J. Lyon, Playing God in the Nursery 51–52 (1985).

[60] Caplan, *Is It a Life?* The Nation, Jan. 21, 1984, at 37, 37.

[61] Baer, *The Half-told Story of Baby Jane Doe,* Col. Journalism Rev., Nov.-Dec. 1984, at 35, 38.

[62] Horan & Balch, *Infant Doe and Baby Jane Doe: Medical Treatment of the Handicapped Newborn,* 52 Linacre Q. 45, 54 (1985). Healing of the spinal lesion is rare without surgery but not without precedent.

[63] *Quoted in* Lyon, *supra* note 59 at 55.

[64] *Baby Jane Doe Goes Home,* Milwaukee J., Apr. 6, 1984, pt. 2, at 3, col. 1.

[65] *'Adorable' Baby Jane Doe Finally Is Home,* Milwaukee Sentinel, May 25, 1984, pt. 1, at 8, col. 1.

[66] Associated Press, *"Baby Doe" Parents Applaud Supreme Court Ruling,* Domestic News PM Cycle, June 10, 1986.

> She has recently begun to demand more than her share and often resorts to throwing toys or M&Ms when the focus shifts away from her. Then she whispers, "I'm bad," aware that her mother is displeased with her behavior.
>
> . . .Later, she whispered, "Dance, Daddy, dance," as her father swept her into his arms to sway to the music of Stevie Wonder.[72]

A woman who works in parent support in Phoenix, Arizona, told the Commission about a similar story:

> We also have our own little Baby Doe in Arizona and her name is Jessie. . .Jessie was supposed to die the first night that she was born. She also had spina bifida, hydrocephalus, lots of severe brain damage, and all of those things that were not compatible with life, so no treatment was done for Baby Jessie. Days and days and days went on and Baby Jessie fooled everybody and did not die.
>
> Finally about the 21st day, right at the time the signs were hanging up in the nurseries, somebody got real nervous and said, maybe she's not going to die, maybe we better do surgery. So by this time, unfortunately it was really too late to do much repair on her back, but they did put a shunt in and that little girl now talks in sentences and goes to regular preschool.
>
> Her family really believed what the doctors said: She will die. So they just waited for her to die. And so for me as a parent I have a real difficult time with someone making that kind of a prognosis for a child and not doing any treatment. Because I have seen too many kids who defy all the prognoses made for them.[73]

One family in the Chicago area can give two examples of negative predictions disproved. They are the adoptive parents of a child with spina bifida left to die in Robinson, Illinois, until the Justice Department intervened.[74] When he was a year old, the *Chicago Tribune* reported that his adoptive parents "believe that his alertness proves there has been no brain damage and that his paralysis from the knees down won't keep him from walking."[75] Their other example is their child born a few years earlier:

> "When she was 4 months old, the doctor told us she had some kind of neurological impairment—they still don't know exactly what. They advised us to put her in an institution and forget about her," said the mother.
>
> The child is now an alert, active 5-year-old who moves normally around the house, and speaks many words, with only slight hesitation.[76]

Patricia McGill Smith, deputy director of the National Information Center for Handicapped Children and Youth, told the Commission about a case in Omaha, Nebraska. A child was born with spina bifida, and there was "a recommendation of no treatment based on the fact that the child had spina bifida and predictable mental retardation." After 4 months of debate, the parents changed their initial decision to accept that recommendation, and the child received treatment and lived. Ms. Smith testified, "I have tracked the progress of that child and that family ever since. The young lady had no mental retardation whatsoever."[77]

Such positive results for children born with spina bifida are not anomalous. Dr. David McLone, who heads a major neurosurgical department and formerly chaired the Professional Advisory Council of the Spina Bifida Association of America, testified:

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[67] Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, Newsday, Dec. 7, 1987, at 2.

[68] Kerr, *Baby Doe's Success*[:] *Legal, Medical Legacy of Case*, Newsday, Dec. 7, 1987, at 2, 23.

[69] Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, Newsday, Dec. 7, 1987, at 2, 23.

[70] Kerr, *Baby Doe's Success*[:] *Legal, Medical Legacy of Case*, Newsday, Dec. 7, 1987, at 2, 23.

[71] Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, Newsday, Dec. 7, 1987, at 2, 23.

[72] *Id.*

[73] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 264–65 (1986) (vol. II) (testimony of Betsy Trombino).

[74] Telephone interview with Robert D'Agostino, Former Deputy Assistant Attorney General, Civil Rights Division, Department of Justice (Dec. 1, 1988).

[75] Nelson, *2d miracle baby gives family joy*, Chicago Tribune, Apr. 24 1983, Sec. 3, at 1, col. 1.

[76] *Id.*

[77] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 254–55 (1986) (vol. II) (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).

> [S]ince I have been at Children's Memorial Hospital, [we have]. . .operated on all children and have not used any form of selection.
>
> . . .85 percent of them survived and 15 percent of the children have died from complications. . . .Of the 85 survivors, 73 of them have normal intelligence. Approximately 85 percent of them have a shunt for their hydrocephalus.
>
> Eighty-nine percent of the survivors are community ambulators. . . .someone who can walk from the school bus to the classrooms, between classrooms, and can walk in their neighborhood. A significant number of those children who are community ambulators, however, are walking with braces and crutches. We have a very small number of children who are in wheelchairs. Ninety-five percent of them have no bladder and bowel control, but are rendered socially continent of bladder and bowel by training in the use of intermittent catheterization. We would, therefore, estimate, based on these numbers, that something like three-quarters of the children who survive will be competitive and independent as adults.
>
> There will be another 10 percent. . .who will require some kind of sheltered care, and about 10 percent of the survivors will be impaired to the point that they will require some kind of nursing care throughout their life.[78]

Despite these results, Dr. McLone observed:

> One of the problems. . .with spina bifida is that a pediatrician in practice may see one or two of these in an entire lifetime. . . . [T]here still are occasions in which physicians are confronted with spina bifida who are not aware of the outcome or the changes that have occurred over the last 20 or 30 years and give information based on what the outcome was 30 or 40 years ago. It's just not appropriate.[79]

Ed Roberts, president of the World Institute on Disability, testified before the Commission:

> I began to be a principal in physical disability. . .at 14 years of age. I got polio in 1953. Within 2 or 3 days, I went from a child who was achieving his independence to patient and to the label of a helpless cripple, and within 2 days I was in an iron lung. My mother went to a doctor and she asked whether I would live or would I die, and the doctor looked at her and very patronizingly said, "Maybe you should hope he dies, because if he lives he'll be nothing more than a vegetable for the rest of his life."
>
> . . . .
>
> One of the real ironies is when I was about 18 years old, I went to the California Department of Rehabilitation and I asked to be a client, and I was immediately rejected as too severe to ever go to work. Well, I became director of that department 10 years later.[80]

John Kemp, a lawyer, testified: "I was born without arms or legs,. . .and my parents were told. . .by the doctor that delivered me. . .that the best I could hope for would be a life of, hopefully of comfort, but certainly not of any kind of achievement."[81]

Robert Williams is deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens, with monitoring responsibility for implementation of a court decree requiring transfer of many people with disabilities from institutions to community living arrangements. He has cerebral palsy with a speech impairment. He testified:

> My parents were told from the start just how severe my disability was. In fact, they were advised on numerous occasions to put me away in. . .an institution. . . .
>
> . . .I come from solid blue-collar stock. My Dad and two brothers own and operate a small construction company. . . .It was clear from the start that I would not be cut out for such a life. My parents decided if I was to make it, I would have to do it by a different way and they provided me with ample support on my journey. As it turned out, I'm the first in my family to graduate from college, the first to have taken an active interest in politics, the arts, and literature.[82]

Another person with a disability who testified was Irving Kenneth Zola, who now teaches sociology at Brandeis University. After he had polio, he used canes with leg and back supports for walking; his rehabilitation agency advised him to go to a vocational school, and people at the agency "were upset when I was accepted at Harvard University."[83] Mary Jane Owen was once told that her daughter was mentally retarded; she later graduated cum laude from Harvard.[84]

Margaret Burley told the Commission about her 24-year-old son who "was diagnosed at various times in his life as having an IQ of somewhere between 5 and 42. . . .He is totally blind, somewhat hearing impaired. . . .It has been said he is emotionally disturbed. He has had every label you would want to put on him. . . ." When he was young, medical personnel told her that he would adversely affect her other three children and urged her to "put him away." She testified, however, that he now works 5 days a week and enjoys going to rock and roll concerts and nightclubs with friends. "[H]e can enjoy life. . . .He is just like anybody else, and I will tell you my other children have turned out to be better citizens, and I think our whole family has been improved [by his presence]."[85]

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[78] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 6–7 (1985) (vol. I) (testimony of David McLone, M.D., Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

[79] *Id.* at 10.

[80] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 102–03, 104 (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability).

[81] *Id.* at 123 (testimony of John Kemp, Director of Human Resources, National Easter Seal Society).

[82] *Id.* at 269–70 (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens).

[83] *Id.* at 178 (testimony of Prof. Irving Kenneth Zola, Department of Sociology, Brandeis University).

[84] *Id.* at 137 (testimony of Mary Jane Owen, Director, Disability Focus, Inc.).

Special Education Professor H. Rutherford Turnbull, himself the parent of a child with mental retardation, has analyzed letters written to the Department of Health and Human Services as part of the public comment on the "Baby Doe" regulations under section 504. Letters written by people with disabilities or their family members described a number of instances in which pessimistic predictions made by physicians were later proved inaccurate. Thirty percent of the correspondents indicated a lack of confidence in health care providers.[86]

The Limitations of Medical Experience

Why do so many negative predictions about the future quality of life of children with disabilities turn out to be wrong? Considerable evidence points to a significant tendency among health care providers to underestimate the capacities of children with disabilities and erroneously to convey unduly pessimistic prognoses to parents about their projected quality of life.

In the words of Surgeon General Koop, "[N]o pediatrician can be expected to know what all of the community supports are that might be available to a child with a given diagnosis. He might understand hemophilia perfectly well in the community, but not cystic fibrosis."[87] Dr. Koop continued, "Therefore, it has been my lifelong endeavor to prevent snap diagnoses, prognostications made without sufficient knowledge. . . ."[88]

Dr. David McLone testified:

> [W]hen you look at the criteria that have been used, such as a child who has a T-12 level shouldn't be operated on—Dr. John [Lorber], a pediatrician from England, is the one who first advanced that criterion—when you look at the results that he published in 1981, in which he treated something like 30 percent of the entire population—if you look at those 30 percent survivors and compare them to our study in which we treated essentially all children, they are not significantly different. So the selection criteria that have been used to select these children that is supposed to be predictive of quality of life or outcome have been shown in almost every center in the United States to be invalid and not predictive and do not produce a population of children with spina bifida who are superior to the group where everyone is treated.[89]

Wolraich, Siperstein, and O'Keefe surveyed random samples of pediatricians on their assumptions about persons with varying degrees of mental retardation. They asked pediatricians to describe specific skills that each group could be expected to develop and compared their answers with those of physician members of the American Association on Mental Deficiency (now the American Association on Mental Retardation, or AAMR). They then compared the answers of each of the two groups with those of special educators and social workers who were also members of the association. "Pediatricians were strikingly restrictive in their expectations of the capabilities of severely mentally retarded individuals. Their categorizations placed these individuals as devoid of most human capabilities, including the ability to sustain friendships; pediatricians believed they were unlikely to work in any setting or reside outside an institutional setting."[90] The pediatricians had significantly more pessimistic expectations than the physician members of the AAMR, who in turn had significantly lower expectations than the special educator and social worker members.[91]

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[85] *Id.* at 257-58 (testimony of Margaret Burley, Director, Ohio Coalition for the Education of Handicapped Children).

[86] *Id.* at 42-43 (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas). Professor Turnbull's written statement excerpts a number of these letters. *See* app. B. It also cites a number of publications and research studies that document "the positive quality of life that people with severe to mild physical or mental disabilities can have and do have." *Id.*

[87] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 8 (1985) (vol. I) (testimony of C Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

[88] *Id.*

[89] *Id.* at 12 (testimony of David McLone, M.D., Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

[90] Wolraich, Siperstein & O'Keefe, *Pediatricians' Perceptions of Mentally Retarded Individuals*, 80 Pediatrics 643, 647 (1987).

[91] *Id.* at 648. *See also Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 49 (1986) (vol. II) (testimony of Carlton Sherwood) (As a result of

Another survey by Siperstein, Wolraich, Reed, and O'Keefe queried a random sample of Fellows of the American Academy of Pediatrics on their views of the future for a child born with spina bifida without hydrocephalus and with hydrocephalus of varying severity.[92] The differences in projection based on degree of hydrocephalus were great. For example, 47.9 percent thought the child without hydrocephalus would live in an unsupervised apartment; only 2.1 percent believed such a child would require institutionalization. On the other hand, the child with severe hydrocephalus was expected by only 2.9 percent to live in an unsupervised apartment and by 54.3 percent to live in an institution. Similarly, 53.8 percent thought the child without hydrocephalus would have skilled competitive employment, with 5.0 percent predicting that such a child would be incapable of any employment. Fully 66 percent stated that the child with severe hydrocephalus would be incapable of any employment, and only 2.3 percent predicted that the child could enter skilled competitive employment. Only 4.6 percent believed the child with severe hydrocephalus would be capable of any type of unsupervised employment.[93]

Evidently most of the pediatricians thought that as the degree of hydrocephalus increases, so does the degree of mental retardation, and also believed that as the degree of mental retardation increases, the capacity for independent and productive living decreases.[94] However, as the authors of the study pointed out, the pediatricians were wrong:

> Yet the findings concerning the effect of hydrocephalus on the intellectual abilities of children born with meningomyelocele indicate a discrepancy between what the pediatricians perceived as the impact of hydrocephalus and current information about the actual impact.
>
> In contrast to the pediatricians' prognoses for mental retardation, actual follow-up studies of children with meningomyelocele accompanied by hydrocephalus have found that the intellectual capabilities of these children are difficult to predict. Although there is an increased chance that there will be some intellectual impairment, other factors, such as shunt infection, are more important. In fact, five studies found no clear relationship between intelligence and the degree of hydrocephalus. Even if there is a relationship between hydrocephalus and mental retardation, as one study did find in correlating the palladium thickness to subsequent intelligence, it does not appear that the degree of mental retardation is as low as pediatricians perceive it to be. When the degree of mental retardation was determined by calculating the mean intelligence quotient scores for children with meningomyelocele and varying degrees of hydrocephalus, most children with severe hydrocephalus had mild to moderate retardation (mean IQ 57.6). In contrast, the pediatricians in this study predicted that those children were likely to function at a much lower level. "Thus it appears that pediatricians have an unduly pessimistic perception about the eventual intellectual abilities of children born with meningomyelocele who have severe hydrocephalus."[95]

Physicians may have such a propensity for negative prognosis at least in part because they tend to see children with disabilities at the time that the children are fighting medical problems, when they are in the hospital—when their condition is at its worst.[96] Those who have contact with people with disabilities on a more regular basis, when they are not in an immediate medical crisis—such as their teachers, coworkers, and family members—tend to have much more positive views of their abilities. According to Dr. Darling: "[T]he few pediatricians who are wholeheartedly in support of treatment for the disabilities that I have known have all, interestingly enough, had a sibling or other close family member who did have a disability."[97] In the sample Dr. Darling studied, however, only 7 percent of the pediatricians had a close family member who had a disability.[98]

Unfortunately, despite the many instances in which pessimistic quality of life projections have been proved dramatically wrong, all too frequently

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his investigations, Sherwood concluded, "[D]octors frequently exaggerate the degree of the handicapped newborn's illness in an effort to justify their decisions and their prejudices.") A possible explanation is that physicians are most likely to see persons with disabilities only when they are sick. *See infra* notes 96–97 and accompanying text.

[92] Siperstein, Wolraich, Reed & O'Keefe, *Medical Decisions and Prognostications of Pediatricians for Infants with Meningomyelocele*, 113 The Journal of Pediatrics 835 (1988).

[93] *Id.* at 838, table 2. The results in this table are reprinted in chap. 4 of this report.

[94] Chap. 4 includes a detailed analysis and empirical refutation of the latter assumption.

[95] Siperstein, Wolraich, Reed and O'Keefe, *supra* note 90, at 839 (footnotes omitted).

[96] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 115 (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability).

[97] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 186 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.). Dr. Darling commented, "I think that the experience of getting to know a person with a disability is a significant experience in changing the way a person views that situation. . . ." *Id.*

[98] *Id.* at 183.

the prophecies themselves help to bring about what they predict. As Ed Roberts testified: "People who are fundamentally seen as less than they are often accept that. It becomes very self-fulfilling when you're put away or put in a nursing home; you begin to accept it."[99]

Dr. Rosalyn Benjamin Darling, who has conducted studies of the physicians and families of children with disabilities, testified that these negative attitudes are often based on the nature of the individual's background.[100] Surgeon General Koop expressed a similar view:

> The snap judgment by the physician. . .can be based upon ignorance. It can also be based upon prejudice. And that prejudice might be of two kinds. One, having seen a similar patient in the past that he didn't think had the quality of life that he liked, he might advise that family that nothing should be done. Or his prejudice may be along the lines, which I think is more common, and that is a stranger looking at a defective newborn baby says, "Gee, if that were mine, I couldn't hack it." But it isn't his, and the parents feel quite differently about their child than a strange physician.[101]

Families, Society, and Persons with Disabilities

The quality of life argument extends beyond the life of the person with a disability. It is frequently argued that the continued existence of a person with disabilities will damage the quality of life of the person's family, or of society as a whole.[102] In other words, the burden the person creates for others outweighs the benefits they experience because she or he exists. Dr. Ellison testified:

> I do think that factors, such as if you have to take home a child who requires 24-hour nursing care,. . .and society provides no other person but the mother and the father, but mostly the mother to do that, that is to say, there's no respite care, there's no homemaker service, there's no one else who is going to care for that child, and in addition to that, the family has to pay for a good many of the medical expenses for that, I think the family ought to be permitted to participate in that discussion and in that decision.[103]

A letter submitted for the record by Dr. Walter Owens (who delivered Bloomington's Infant Doe) exemplifies a willingness to make denial of treatment decisions based on the utility of the life to others. The anonymous woman followed Dr. Owen's 1971 advice to deny treatment to her child born with spina bifida, hydrocephalus, and unspecified "other anomalies."

> I don't think I would be able to have the happy, complete quality of life I have now if I had not made the proper decision about that baby, based on your wise and compassionate counsel. My decision might seem self-serving to some, but in my heart, I truly feel that I made that choice based on that baby's lack of potential for a meaningful life, and yes, for my own need for a full life too.[104]

Similarly, in the Bloomington Infant Doe case itself, the trial court's opinion reveals that the father "testified that. . .he and his wife have determined that it is in the best interest of the Infant Doe and the two children who are at home and their family entity as a whole" that the child should not be provided lifesaving surgery.[105]

Children with disabilities, thus, are alleged to have a negative effect on their parents' qualities of life. Dr. Darling's research indicates that the sort of parental attitude exemplified by Dr. Owen's correspondent and the father of Bloomington's Baby Doe tends to change over time and with increased interaction with the child:

> Parents. . .start out with the same kind of. . .stigmatizing attitude physicians have. . . .
>
> . . .Even though the initial experience tends to be negative, usually within a short period of time, attitudes turn around.
>
> Parents realize that this child is just as lovable as anybody else's child, and they begin to see positive aspects

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[99] *Id.* at 105 (testimony of Ed Roberts, President, World Institute on Disability).

[100] *Id.* at 188–89 (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

[101] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 11-12 (1985) (vol. I) (testimony of C. Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

[102] See chap. 4 for a discussion of the economic effect on society as a whole.

[103] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 223 (1986) (vol. II) (testimony of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver).

[104] Letter from anonymous person to Dr. Walter Owens (Aug. 20, 1983) (available in Commission files).

[105] *In re* Treatment and Care of Infant Doe, No. GU 8204–004A, slip op. at 2 (Monroe Co. Cir. Ct. Apr. 12, 1982), *reprinted in Declaratory Judgment in the Infant Doe Case,* 2 Issues in L. & Med. 77, 79 (1986), *petition for writ of mandamus and prohibition denied sub nom.* State of Indiana *ex rel.* Infant Doe v. Monroe Circuit Court, No. 482 S 140 (Ind. Apr. 14, 1982), *appeal dismissed sub nom. In re* Guardianship of Infant Doe, No. 1-782A 157 (Ind. Ct. App. Feb. 3, 1983), *petition for transfer denied.* No. 1-782 A 157 (Ind. June 15, 1983), *cert. denied,* 464 U.S. 961 (1983).

> of life with a child who is disabled. Many parents have said that it has become a maturing kind of process with them. Living with a problem that can't be solved is a very maturing kind of thing. Many become exposed to a whole world of people and activities that they never knew existed before. Once it happens, they learn to make the best of it, and even learn to find some positive aspects of it and those aspects are the very things parents don't hear right at the beginning in that decisionmaking situation. . . .[106]

In both the Baby Jane Doe case of 1983–84[107] and the Milwaukee Baby Doe case of 1987[108] the parents ultimately decided to provide the lifesaving surgery courts had ruled they could legally deny.

The deputy director of the National Information Center for Handicapped Children and Youth, referring to comments concerning burdens imposed on parents by the continued life of children with disabilities, testified:

> I have supported hundreds of parents over the 12 years that I have worked, and when parents are supported in the help to their children, and when the medical support is given, even for severely handicapped children, I have not met a parent yet that does not want to do it if they can. And I think it is our job to make sure that they have those supportive services.[109]

Propriety of Quality of Life Judgments

The deficiencies in quality of life assessments are demonstrated above. The more fundamental question is: to what extent should quality of life judgments be viewed as acceptable grounds for life and death decisions?

There is an important difference between technical medical judgments about whether a given course of treatment is likely or not to preserve life or ameliorate an impairment, and judgments about whether a person's life should or should not be preserved by giving lifesaving treatment. The first sort of judgment is one that is uniquely medical in nature. The second sort of judgment is not, properly speaking, a "medical" one. It is a social judgment about the value or desirability of particular people's lives. This no more becomes a "medical" judgment by virtue of its implementation through the denial or provision of medical treatment than the decision whether to impose capital punishment becomes a "medical" judgment if execution is to be by lethal injection.[110]

Disability rights advocates argue that to take into consideration the burden that children with disabilities might impose on their families or society in deciding whether they should live or die constitutes discrimination on the basis of disability. Adrienne Asch testified:

> [D]isabled people. . .have separate interests and civil rights apart from any family, societal, economic, social, or emotional burden that they might cause. Other people cause burdens, too, but we don't consider whether they should be alive, if it is all right with someone else. . . .We talk about the burden that disabled people will cause to their families, to their siblings, as though it means that the only way that disabled children should be allowed to live is if it is all right with someone else.[111]

Recent decades have seen significant although mixed progress in understanding the burdens that society places on people with disabilities and in recognition of their rights and full humanity. At the Federal level, section 504 of the Rehabilitation Act of 1973[112] applies a general principle of nondiscrimination based on handicap to all programs or activities receiving Federal financial assistance; the Education for All Handicapped Children Act of 1975[113] promises to all children with disabilities a "free appropriate public education which emphasizes special education and related services designed to meet their unique needs"; the Developmental Disabilities Assistance and Bill of Rights Act[114] gives the Nation's assurance "that all persons with developmental disabilities receive the services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community"; and the Architectural Barriers Act of 1968[115] is intended to make public buildings physically accessible to people with disabilities.[116]

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[106] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 184–85 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

[107] *See supra* text accompanying notes 54–72.

[108] *In re* T.A.P., No. 03231186 (Milwaukee County, Wisc. Cir. Ct. July 31, 1987), *rehearing* (Aug. 12-13, 1987).

[109] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 256 (1986) (vol. II) (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).

[110] *See id.* at 116–17 (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico); *id.* at 202 (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

[111] *Id.* at 126 (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

[112] 29 U.S.C.A. §794 (West Supp. 1988).

[113] 20 U.S.C.A. §1401 note (West 1978 & Supp. 1988).

[114] 42 U.S.C.A. §§6000–6083 (West 1983 & Supp. 1988).

It is the interpretation of the Department of Health and Human Services, the Federal agency charged with implementing the Child Abuse Amendments of 1984, that "the law [does] not permit life and death treatment decisions to be made on the basis of subjective opinions regarding the future 'quality of life' of a retarded or disabled person."[117] Before passage of the Child Abuse Amendments, nine major disability and medical associations adopted a set of "Principles of Treatment" that also rejected the use of quality of life criteria: "Considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care."[118]

Conclusion

The bases typically advanced to support denial of lifesaving medical treatment, food, and fluids based on disability—that the quality of life of a person with a disability will be unacceptably poor, or that such a person's continued existence will impose an unacceptable burden on his family or on the Nation as a whole—are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities. A country committed to the civil rights of all should address the very real problems people with disabilities and their families face through fostering supportive services and social acceptance, and through defending their rights to accessible and integrated transportation, housing, education, health care, and employment—not by eliminating those with disabilities.

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[115] 42 U.S.C.A. §§4151 to 4157 (West 1977 & Supp. 1988).

[116] *See generally* U.S. Commission on Civil Rights, Accommodating the Spectrum of Individual Abilities 46–62 (1983).

[117] Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14879 (1985). *See also id.* at 14880; 45 C.F.R. pt. 1340 App. Interpretative Guideline 9 (1987); chap. 7.

[118] *Joint Policy Statement: Principles of Treatment of Disabled Infants*, 73 Pediatrics 559, 559 (1984). The cosigning organizations were the Association for Retarded Citizens, the National Down's Syndrome Congress, the American Coalition of Citizens with Disabilities, Inc., the Association for Persons with Severe Handicaps, the American Association on Mental Deficiency, the American Association of University Affiliated Programs for Persons with Developmental Disabilities, the Spina Bifida Association of America, the National Association of Children's Hospitals and Related Institutions, Inc., and the American Academy of Pediatrics. However, the American Academy of Pediatrics has since argued, with regard to the Child Abuse Amendments, that Congress did not "clearly intend[] to exclude consideration of the infant's quality of life." Comment of the American Academy of Pediatrics on Proposed Rules Regarding Child Abuse Neglect Prevention and Treatment Program 30 (Feb. 8, 1985), *quoted in* Nicholson, Horowitz & Parry, *Model Procedures for Child Protective Service Agencies Responding to Reports of Withholding Medically Indicated Treatment from Disabled Infants With Life-Threatening Conditions.* 10 Mental & Physical Disability L. Rep. 220, 227 (1986).

Chapter 4

The Role of Economic Considerations in Denials of Medical Treatment

An argument frequently heard in favor of denial of treatment is the claim that the costs associated with children born with disabilities create a burden too great to be borne by family or society.

For example, Dr. Walter Owens, the physician in attendance during the death of Bloomington's Infant Doe, told the Civil Rights Commission:

> In an ideal society, one might say we should consider only the welfare of the child, but this is not an ideal world and we do not have unlimited resources. . . .
>
> Money which is spent—and we're talking of many times $100,000 or even $500,000 or even $1 million spent on such children—that is money not available for the education of normal children.[1]

A similar perspective was articulated by Dr. George Crile, former head of the Department of General Surgery of the Cleveland Clinic, who argued in 1984, shortly after passage of the Child Abuse Amendments:

> Despite the law, the debate. . .continues. . . .[The question] must be viewed. . .in the light of. . .society's right for its members to have productive and pleasant lives, not to be lived mainly to support the growing numbers of hopelessly disabled, often unconscious people whose costly existence is consuming so much of the gross national product. . . .[2]

If a child is born with Down syndrome, Crile wrote:

> parents can be told that their child has no chance of growing up to be able to take care of itself. If the parents still want to rear their child, that should be their decision, but there should be no support from the community or the state.
>
> I wish to emphasize that I do not believe that existence is necessarily unhappy for the child with Down's nor that such a child cannot be a joy to its parents. That is why the parents should make the final decision. It remains that a child with Down's syndrome. . .will not grow up to be self-sustaining or able to contribute to the economy. Neither the community nor taxpayers should be obliged to support the child.[3]

Similar thinking is found in an article on cost-benefit analysis published in July 1984 in the journal of the American Academy of Pediatrics.[4] The article was written by doctors and researchers affiliated with the Women and Infants Hospital of Rhode Island and Brown University.

This cost-benefit analysis was based on the records of 247 infants who weighed between 500 and

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[1] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 205–06 (1986) (vol. II) (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.).

[2] Crile, *The Right to Life*, Med. Tribune, Dec. 19, 1984, at 27. Commenting on a draft of relevant portions of this report, Dr. Crile charged that this quotation gives a "false impression" of his position because he has "never stood against rehabilitation of any one with a brain that was functional or a body that was salvageable. . . .I am referring to people who are *hopelessly* disabled, and that means disabled to the extent that rehabilitation could not help them to improve or recover." Letter from George Crile, Jr., M.D., to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Sept. 15, 1988) (emphasis in original), *reprinted in* app. D. As his article (which is reprinted in full in app. D) makes clear, however, Dr. Crile's notion of a hopelessly nonfunctional brain is broad enough to include "totally incurable and accurately diagnosable brain defects such as Down's syndrome." Crile, *supra*, at 27.

[3] *Id.* For a consideration of the validity of such claims about those with Down syndrome, see chap. 3.

[4] Walker, Feldman, Vohr & Oh, *Cost-Benefit Analysis of Neonatal Intensive Care for Infants Weighing Less Than 1,000 Grams at Birth*, 74 Pediatrics 20 (1984).

999 grams at birth and who were born between January 1977 and December 1981. Eighty-seven percent of the survivors were evaluated for from 1 to 5 years. Most (74 percent) were unimpaired or minimally impaired. Ten percent were "moderately impaired" and 16 percent were labeled "severely handicapped." Their projected lifetime costs (estimated in 1982 dollars) ranged from $362,992 for the lowest birthweight group—600 to 699 grams—to $40,647 per survivor for those in the highest birthweight group—900 to 999 grams. Lifetime earnings were estimated at zero for those in the 500 to 699 gram birthweight group and $77,084 for those in the highest birthweight group of 900 to 999 grams.[5]

The authors concluded that "neonatal intensive care may not be justifiable for infants weighing less than 900 grams at birth."[6] They reached this conclusion even though 63 percent of the 700 to 799 gram and 57 percent of the 800 to 899 gram birthweight groups had no or minimal disabilities.[7] They did so by straightforwardly comparing their estimates of the cost of lifetime care to their estimates of lifetime earnings.[8]

Cost-benefit analysis as a justification for denial of treatment to people with disabilities implies discrimination based on disability, because such evaluations are not typically employed in other contexts.[9] The Commission emphatically rejects the view that lifesaving medical services should be provided or denied to any group of people based on their estimated economic worth to society. The Commission considers it important, however, to give critical examination to the factual premises of an argument for denial of treatment that is made as frequently as is the economic one.

Underlying most cost-benefit projections are two superficially plausible assumptions: (1) the more serious the level of disability, the poorer the prognosis for residential placement and productive employment; and (2) the poorer the prognosis, the higher the net cost of lifetime care.[10]

This approach is based on what may be called a "mythology" of disability, a mythology grounded in the basic assumption that the circumstances of disability (i.e., the living arrangements and work and social opportunities for those who have disabilities) emanate from the disability itself, and hence the costs associated with these arrangements are the direct result of the disability. However, as shown below, this assumption has been refuted during the past 10 years by the performance of people with disabilities.

The importance of the assumptions that underlie this mythology in the practice of denial of treatment should not be underestimated. To understand and critically appraise estimates of long term care or public costs associated with severe disability as they appear in the medical literature, it is important to recognize how dependent these estimates are on assessing the potential of the individual with the disability.

A recent medical journal article reported the results of a random survey of 604 Fellows of the American Academy of Pediatrics. Of the 604 pediatricians contacted, 373 or 62 percent returned the questionnaires; 56 of these were discarded due to incomplete information.[11]

One series of questions inquired what each doctor thought the future would be like, in terms of their residential placement and potential for work, for children with spina bifida. Approximately half the doctors were asked to make predictions about children born with spina bifida but no hydrocephalus and those with spina bifida and moderate hydrocephalus; the other half were asked to make predictions about those with no hydrocephalus and those with severe hydrocephalus. That is, the questionnaire ascertained where the doctors thought each of these examples of disability would place a child on the spectrum from relative independence in living and working all the way to total dependence with no hope of securing employment.

The results of this survey, undertaken to determine how pediatricians would influence treatment decisions based on the presence of varying degrees of hydrocephalus in children born with spina bifida, suggested that most pediatricians assume that moderate hydrocephalus leads inexorably to a lessened

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[5] *Id.* at 20.

[6] *Id.*

[7] *Id.* at 22 (table 3).

[8] *Id.* at 20.

[9] For example, we do not routinely compare the costs juvenile delinquents are likely to cause society with their probable economic benefits and then choose death for those with regard to whom the costs are calculated to exceed the benefits.

[10] As later portions of this chapter demonstrate, such assumptions are inaccurate in light of the progress made in the last decade that has enabled even those labeled most severely disabled to live in community settings and to become productive members of society.

[11] Siperstein, Wolraich, Reed, & O'Keefe, *Medical Decisions and Prognostications of Pediatricians for Infants With Meningomyelocele*, 113 J. of Pediatrics 835 (1988).

TABLE 4.1

Pediatricians' Responses to the Prognostic Belief Scale

	Infant without hydrocephalus n = 317	Infant with moderate hydrocephalus n = 139	Infant with severe hydrocephalus n = 178
Prognostication for Adult Capabilities			
Mean Score	21.7	15.8	6.4
Standard Deviation	6.1	8.0	7.1
Prognostications for Residential Placement			
Unsupervised apartment	47.9%	18.5%	2.9%
Supervised apartment	35.7%	31.1%	12.0%
Group home	14.2%	31.1%	30.8%
Institution	2.1%	14.5%	54.3%
Prognostications for Vocational Placement			
Skilled competitive employment	53.8%	19.7%	2.3%
Unskilled competitive employment	5.6%	6.6%	2.3%
Supervised full-time employment	20.9%	25.4%	7.6%
Supervised part-time employment	14.7%	31.1%	21.5%
Incapable of any employment	5.0%	17.22%	66.3%

Source: Siperstein, Wolraich, Reed & O'Keefe, *Medical Decisions and Prognostications for Infants with Meningomyelocele*, 113 Journal of Pediatrics 838 (1988). Reprinted with permission.

ability to live independently (say only in a supervised apartment or group home) and that severe hydrocephalus leads just as inexorably to life in an institution. (See table 4.1.) They make similar assumptions concerning the child's ability to work—that moderate hydrocephalus makes only supervised employment possible, while severe hydrocephalus means no employment at all.[12]

It is not surprising that these predictions result in a tendency by pediatricians to incline away from encouraging lifesaving surgery toward discouraging it as hydrocephalus becomes more severe. Although 34.2 percent of the pediatricians would either not know what to do or would provide only supportive care if the child were their own and had spina bifida without hydrocephalus, 75.7 percent would not know what to do or would provide only supportive care if their child had spina bifida with severe hydrocephalus.[13]

Costs of Residential Placement

A recent study of the costs of residential placements for over 1,000 persons with severe disabilities in three States calls into question the assumption that the more severe the disability, the greater the cost of residential placement.

> The objective of [the project] was to identify differences in costs associated with providing services to persons in different types of residential arrangements and with varying levels of disability. Accordingly, in selecting service systems for study, the aim was to identify systems embracing a variety of residential service options.
>
> Two of the three regional systems have been recognized by the University of Syracuse Center on Human Policy as "model" residential programs. The third, in New Hampshire has been widely recognized for its commitment to serve persons with all levels of disability in small community-based living arrangements and integrated work settings.[14]

Each system relies on a broad range of integrated community homes, including group homes, apartments, and family-type homes. Using data from 1984–85 and 1985–86, the study examined costs for 1,287 individuals living in 169 group homes, 151 family homes, and 43 apartments.[15] Cost data were also examined for approximately 250 persons from these three regions living in institutions.[16] Each individual was identified on a scale of 1 to 100 to determine similar and differing levels of disability.[17]

The study concluded: "The average annual cost of residential services per client varied more, far more, by the type of residential option employed than by the level of need of the client."[18] Group homes, apartments, and family-type homes were significantly less costly than institutions for individuals at all levels of disability, including the most severe levels.[19] Persons labeled and considered most disabled, severely and profoundly handicapped by every definition, were found in significant numbers in all four residential options (institutions, group homes, apartments, and surrogate family homes).[20] More persons in the most severe range of disabilities were found in community settings than in institutional ones.[21]

The definition of severe disability used in this study was limited to those individuals who usually had more than one very significant disability. Profound mental retardation alone was not considered enough for a classification of severe disability by any of the regions. For such a classification, a person had to experience severe retardation together with blindness or deafness or complex medical or behavioral needs.[22]

Despite widely divergent cost of living differences and salary differences in the three regions, for all:

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[12] *Id.* at 838, table 2. The article points out that these assumptions are erroneous.

[13] *Id.* at 837, table 1. See chap. 3 (text accompanying notes 92–95) and chap. 9 (text accompanying notes 13–18) for a further discussion of this survey.)

[14] Ashbaugh & Nerney, An Analysis of the Costs of Serving Persons with Mental Retardation by Type of Residential Arrangement: Macomb-Oakland Region in Michigan, Region V in Nebraska, and Region V in New Hampshire 2 (1988).

[15] *Id.* at 2. Costs for Michigan and Nebraska, July 1, 1984, to June 30, 1985; for New Hampshire, July 1, 1985, to June 30, 1986.

[16] Interview with Thomas Nerney, coauthor and project coordinator for the above-referenced study (Nov. 29, 1988) [hereinafter Nerney interview].

[17] Ashbaugh & Nerney, *supra* note 15 at 6.

[18] *Id.* at 14.

[19] Nerney interview, *supra* note 17.

[20] More than 33 percent of the sample met the definition of those considered most severely disabled. *Id.*

[21] *Id.* In Michigan's Macomb-Oakland region, there were five times the number of those considered most severely disabled living in community homes than in institutions.

[22] *Id.*

- The differences in average cost per person per year for those with identical disabilities ranged from over 2 times to as much as 6 times as much from one option to another.[23]
- The average institutional cost was higher than any of the average community costs no matter which community option was chosen and no matter what the level of disability.[24]
- Administrators (public officials) agreed that the most costly option, the institution, was in every case the least desirable programmatically: the person with a disability benefited the least from the institution and in most cases was harmed by it.
- Administrators agreed that family or family-scale placements were always preferable to institutional placements for children.[25]
- The smaller the unit of community residential placement, the lower the average cost incurred, no matter the severity of the disability.[26]
- Family-type placements with appropriate backup supports were the least costly and, for children, the most desirable.[27]

The cost differentials for the same level of disability by nature of residential placement in Michigan's Macomb-Oakland system, Nebraska's Region V system, and Region V in New Hampshire are shown in figure 4.1.

Family Placement

The trend in providing care for those with the most severe disabilities appears to be moving away from the use of high-cost institutional settings to a variety of community-based ones with significant programmatic and fiscal differences. A clear trend in the direction of use of family-type placements, the least costly alternative, is developing, especially for children.[28] It seems probable, therefore, that in real terms the average cost of residential placement for people with disabilities is headed downward, not upward.

Despite the clear cost (and desirability) advantage of family placement, most contemporary Federal and State policies do not encourage it. There are important, often unrecognized, historical reasons for this.

In the early part of this century, the eugenics movement gave rise to the institutional program for persons with disabilities,[29] with most public institutions being established to remove persons with disabilities from their communities and families because they were, mistakenly, thought to be dangerous and responsible for society's ills.[30] The ingrained pattern established by this practice goes a long way toward explaining why it is still so difficult automatically to think of and foster the natural (or adoptive) family as the most humane and logical choice for initial support when a child with a disability is born.[31]

As discussed above in chapter 1, government reports from the early part of this century labeled persons with mental retardation and persons with disabilities generally as "a parasitic, predatory class," "a danger to the race," and "a blight and a misfortune both to themselves and to the public."[32] State laws required persons with disabilities to be removed from the community and parents to surrender their children or allow State officials to take them.[33] In the State of Washington it even became a criminal offense, punishable by a fine, to keep a child with mental retardation at home.[34]

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[23] *Id. See also* Ashbaugh & Nerney, *supra* note 15, at fig. 16 and fig. 35.

[24] Nerney interview, *supra* note 17. For example, in Michigan's Macomb-Oakland system, community placement could result in saving over $47,000 per person per year compared to institutional placement.

[25] *Id. See also Medicaid Home and Community Quality Services Act of 1987: Hearing on S. 1673 Before the Subcomm. on Health of the Senate Comm. on Finance,* 100th Cong., 2d Sess. 5 (1988) (hereinafter *Medicaid Hearing)* (statement of K. Charlie Lakin, Director of Research, Minnesota University Affiliated Program on Developmental Disabilities/Center for Residential and Community Services, Minneapolis, Minn.) (regarding the inferiority of institutions to community-based settings).

[26] *Id. See also* fig. 4.1, with regard to those considered "most severely disabled"; Ashbaugh & Nerney, *supra* note 15, at fig. 16 and fig. 35.

[27] Nerney interview, *supra* note 17.

[28] *Id.*.

[29] Motion and Brief Amici Curiae of Association for Retarded Citizens/USA, Association for Retarded Citizens/Texas, National Down Syndrome Congress, People First International and People First Organizations of Iowa, Louisiana, Michigan, Nebraska, Oregon and Washington, United Together, S.T.A.N.D. Together, Speaking for Ourselves, Consumer Advocacy Board of the Massachusetts Association for Retarded Citizens, Texas Advocates, Wisconsin Advocates, Capitol People First, and Self-Advocates of Central New York at 5–6, Cleburne v. Cleburne Living Center, 473 U.S. 432 (1985) (No. 84–468).

[30] D. Rothman & S. Rothman, The Willowbrook Wars 47 (1984).

[31] *See* chap. 1 and text accompanying notes 36–59.

[32] *See* chap. 1 and text accompanying notes 55–57.

[33] Brief Amici Curiae of the American Coalition of Citizens with Disabilities, People First Organizations of California, Iowa, Louisiana, Michigan, Nebraska, Oregon and Washington, People First International, United Together Organizations of Arkansas, California, Florida, Idaho, Kansas, Massachusetts, Minnesota, and Montana, Speaking for Ourselves of Pennsylvania, Consumer Advisory Board of Massachusetts, Self-Advocates of Central

More enlightened attitudes in recent decades led to some reform. In the early 1970s, Congress allowed the States to begin using Federal medicaid funds to improve the terrible conditions found in institutions.[35] The Federal medicaid route to reform resulted in an enormous investment of Federal and State dollars in the institutions.[36]

Soon, however, members of the disability rights parent and advocacy movement came to the conclusion that these institutions could not be reformed. Instead, they demanded that the individuals residing there return to their communities.[37]

The use of what were originally called "alternatives" to the institutions, i.e., group homes and family homes, became commonplace. A number of States, including Maine, Rhode Island,[38] Michigan, Nebraska, and New Hampshire, established community-based systems.[39] The results were impressive:

> Numerous studies have compared social participation of institution and community residents. They consistently and clearly find community residents to be better integrated. They go to more restaurants, more stores, more movies, more sporting events. They go on more walks off the facility grounds. They visit more often with friends who live elsewhere. They are more likely to have friendships with non-handicapped peers. They have more contact with their own families. In short, they are better integrated in every conceivable way.[40]

These policies, however, did not address the needs of families who kept their children at home.[41] The fiscal incentives to States remained with the institutions first, the community homes a bad second,[42] and the natural family last.[43] Only recently has an attempt been made to change the Federal medicaid legislation to give priority in funding to families and community homes. Legislation to accomplish this, such as the Medicaid Home and Community Quality Services Act of 1987, has yet to be enacted.[44] Because providing support for the family is the most cost-efficient way to provide residential services, changing the economic incentives from the institution to the family would cause the cost associated with disability to drop significantly.

Productivity of Persons with Severe and Profound Disabilities

State vocational rehabilitation agencies, together with advocacy and service agencies, have begun to offer new and experimental job training programs for those with the most profound disabilities.[45] These programs are the result of a relatively new concept in employment training variously referred to as "supported employment" or, for school-age adolescents, "transitional employment."[46] The evidence of earning capacity among people commonly viewed as inherently unproductive after less than approximately 5 years of Federal- and State-funded employment programs is dramatic.

One example is a program run by a nonprofit agency, New England Business Associates. Under the program, a job coach accompanies a person with a severe or profound disability to the place of employment, provides onsite assistance as needed, and helps train the individual while she or he is working at a regular job paid for by an ordinary employer. This job coach fades back as the individu-

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New York, Texas Advocates, Wisconsin Advocates, Disabled in Action of Pennsylvania, Disabled in Action of New York, and the National Association of Protection and Advocacy Systems at 13-14, Bowen v. Am. Hosp. Ass'n, 476 U.S. 610 (1986) [hereinafter ACCD Amicus].

[34] Cleburne amicus, *supra* note 33, at 13.

[35] *See generally* S.B. Sarason & J. Doris, Educational Handicap, Public Policy and Social History (1979).

[36] *Medicaid Hearing, supra* note 26, at 2 (opening statement of Sen. George Mitchell).

[37] *See, e.g.*, Pennhurst State School and Hosp. v. Halderman, 451 U.S. 1, 6 & n.1 (1981); Rothman & Rothman, *supra* note 31, at 49-50.

[38] *Medicaid Hearing, supra* note 26, at 2 (opening statement of Sen. George Mitchell).

[39] Nerney, Nisbet & Conley, Economic Analysis of Three Regional Community Developmental Service Regions (1989) (in press).

[40] *Id.* at 5-6 (statement of K. Charlie Lakin, Director of Research, Minnesota University Affiliated Program on Developmental Disabilities/Center for Residential and Community Services, Minneapolis, Minn.).

[41] *Id.* at 8-9 (statement of Valerie J. Bradley, President, Human Services Research Institute, Cambridge, Mass.).

[42] D. Braddock, R. Hemp & G. Fujiura, Public Expenditures for Mental Retardation and Developmental Disabilities in the United States 50-52 (2d ed. 1986).

[43] National Study Group on State Medicaid Strategies, The Center for the Study of Social Policy (Tom Doe, Director), Restructuring Medicaid: An Agenda for Change 11 (1983).

[44] *See* Medicaid Hearing, *supra* note 26, at 1 (opening statement of Sen. George Mitchell) and 3 (opening statement of Sen. John Chafee).

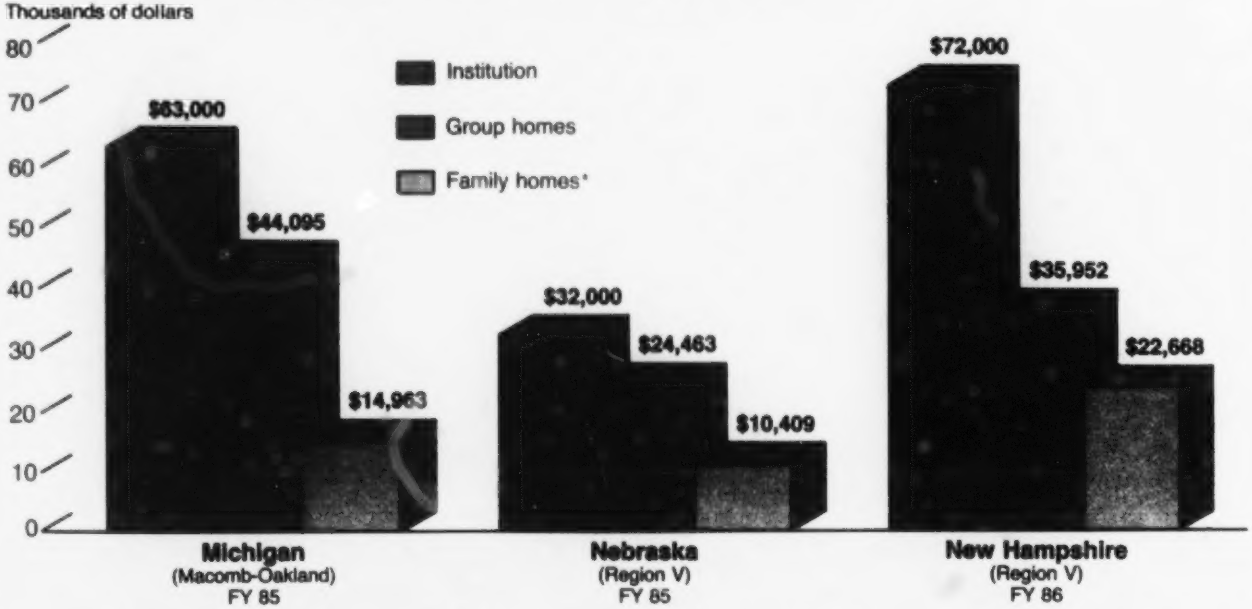
[45] *See generally* Congress Passes Voc Rehab Bill: Supported Work for CMIs E National Association of State Mental Health Program Directors Report: The U.S. Congress, Oct. 7, 1986, at 3-5.

[46] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 88 (1986) (vol. II) (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education).

FIGURE 4.1

Comparative Costs of Institutions, Group Homes and Family Homes in Three States

Average annual per person costs for those considered "most severely disabled"



*Family home refers to individuals and families, not the natural parents, who take a person(s) with severe disabilities into their own home or apartment.

al gains skills and income but remains always available both to the individual with a disability and to the employer.[47]

Kathy Moore, executive director of New England Business Associates, provided the Commission with these examples of people active in the program:

J. C. profoundly deaf, legally blind, severely retarded 1987–88 earnings $7,860.00

M. D. profoundly deaf, legally blind, brain tumor, mentally retarded, institutionalized at birth 1987–88 earnings $6,220.85

M. Gl. profoundly deaf, totally blind, profoundly retarded, institutionalized at birth 1987–88 earnings $7,221.60

M. K. profoundly deaf, totally blind, severely mentally retarded 1987–88 earnings $2,163.00

E. R. profoundly deaf, totally blind, severely retarded, progressive sensory neural loss 1987–88 earnings $10,400.00

L. T. profoundly deaf, totally blind, severely retarded, institutionalized at birth 1987–88 earnings $332.13[48]

A similar program for adults with autism and severe behavioral difficulties has been operating in Montgomery County, Maryland, for almost 8 years. This program, run by Community Services for Autistic Adults and Children, included over 46 persons ruled "unemployable" by every agency they had ever contacted. After living most of their lives in institutions, now all live in small homes in Rockville, Maryland, and all earn at least the minimum wage in a program using supported employment.[49]

An 8-year longitudinal study of the costs and benefits of supported employment for 117 persons with moderate to severe mental retardation found that, in comparison to the $1,361,951 that would have been required in SSI payments and alternative service programs had these persons not been employed, the supported employment program cost $1,212,117. Those participating in the program earned wages totaling $1,503,779.[50] In other words, in place of a net average cost of $11,640.61 for each person with moderate or severe mental retardation, with supported employment there was a net average benefit of $2,492.84 for each such person. The authors of the study pointed out that with ongoing job retention, the net benefit will significantly increase over time, since the costs of supportive employment are substantially frontloaded while the average income is constant or increasing.[51] Furthermore, they noted:

> Our university-based demonstration is very small; in fact, the. . .consumers served over 8 years are unfortunately dwarfed when compared with large day programs in which the sole purpose is to provide vocational or day care services. Consider the dramatic savings in programs, over time, if substantial reorganization of the operations at the centers were converted to community- or industry-based programs. It is in this area where the truly large dollar savings can be made over a multi-year time period.[52]

Conclusion

Disability does entail cost. But the real economic costs now associated with disability are less a function of the disability or its severity than of a policy that tends to segregate and isolate, at enormous public cost, those persons considered most severely disabled. The assumption has been that the level of severity of disability is the major determinant of lifetime costs and, consequently, that the more severely disabled a child may appear to be at birth, the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency and the more expensive it will be to meet that person's basic needs. Although this assumption is unfounded, it has resulted in a self-fulfilling prophecy: a diagnosis of severe disability leads to placement of a person in an institutional and nonwork environment that significantly limits that person's capability and entails far more expense than necessary.

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[47] Interviews with Kathy Moore, Executive Director, New England Business Associates (Sept. 19–20, 1988).

[48] *Id.*

[49] Interview with Susan Goodman, Executive Director, Community Services for Autistic Children and Adults (Sept. 17, 1988).

[50] Hill, Wehman, Kregel, Banks & Metzler, *Employment Outcomes for People with Moderate and Severe Disabilities: An Eight-Year Longitudinal Analysis of Supported Competitive Employment*, 12 J. Ass'n for Persons with Severe Handicaps 182, 185-86 (1987).

[51] *Id.* at 187–88.

[52] *Id.* at 188 (emphasis in original).

Chapter 5

State Law

What is the law governing denial of lifesaving medical treatment to children with disabilities? Every State now provides a statutory basis for the civil authorities to act to protect a child whose life or well-being is threatened by abuse or neglect.[1] In 46 of those States, those that receive Federal funding for child abuse and neglect programs, this law must be applied to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions in order to comply with the Child Abuse Amendments of 1984.[2]

The Child Abuse Amendments were enacted largely because Congress perceived preexisting State law to be inadequate to provide needed protection.[3] To understand this perception, it is helpful to contrast the near unanimity in recent State cases, which have ensured the provision of lifesaving medical care to nondisabled children, with the mixed record of State cases dealing with the withholding of such care from children with disabilities.

Increasing Societal Interest in Protecting Children

Over the past century, the States have significantly expanded their jurisdiction in protecting children. In 1874 a dying woman in New York City pleaded with the parish visitor, Mrs. Etta Wheeler, to go to the authorities about the incessant screams and cries for help of a child in an adjacent apartment. When Mrs. Wheeler finally agreed to do so, the police, district attorney, charitable agencies, and clergy all turned her away. So great was the universal respect for absolute parental autonomy in decisions concerning their children that the only person she could get to help was the counsel for the American Society for the Prevention of Cruelty to Animals, Elbridge Gerry.[4]

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[1] *See* Ala. Code §26-14-1(2) (1986); Alaska Stat. §47.17.070(5) (1984); Ariz. Rev. Stat. Ann. §36-2281 (1986); Ark. Stat. Ann. §9-30-103(5)(A) (Supp. 1987); Cal. Pen. Code §11165(C) (West 1982); Colo. Rev. Stat. §19-1-103(20)(d) (1986); Conn. Gen. Stat. Ann. §46(b)-120(b) (West Supp. 1988); Del. Code Ann. tit. 31, §301(3) (1975); D C. Code Ann. § 16-2301(9)(B) (1981); Fla. Stat. Ann. §39.01(37) (West Supp. 1988); Ga. Code Ann. §15-11-2(8)(A) (Supp. 1988); Hawaii Rev. Stat. §350(1)1 (Supp. 1984); Idaho Code §16-1602n-(1) (Supp. 1988); Ill. Ann. Stat. ch. 37, §802-3(1) (West Supp. 1988); Ind. Code Ann. §31-6-4-3(a)(1) (Burns 1987); Iowa Code Ann. §232.2(6)(e) (West 1985); Kan. Stat. Ann. §38-802(g)(1) (1981); Ky. Rev. Stat. Ann. §199.011(b) (Michie 1982); La. Rev. Stat. Ann. §40:1299.36.1 (West Supp. 1988); Me. Rev. Stat. Ann. tit. 22, §4002(1) (Supp. 1988); Md. Fam. Law Code Ann. §5-701(n)(2) (Supp. 1988); Mass. Gen. Laws Ann. ch. 119, §51A (West Supp. 1988); Mich. Comp. Laws Ann. §722.622(d) (West Supp. 1988); Minn. Stat. Ann. §626.556-2(C) (West Supp. 1988); Miss. Code Ann. §43-21-105(1)(i) (Supp. 1987); Mo. Ann. Stat. §210.110(5) (West Supp. 1988); Mont Code Ann. §41-3-102(3)(C) (1987); Neb. Rev. Stat. §28-710(3)(C) (1985); Nev. Rev. Stat. Ann. §200.508(3)(a) (Michie 1986); N.H. Rev. Stat. Ann. §169-C:3 XIX(b) (Supp. 1987); N.J. Stat. Ann. §9:6-8.21(c)(4)(a) (West Supp. 1988); N.M. Stat. Ann. §30-6-1(A)(2) (1978); N.Y. Soc. Serv. Law §371.4-a(i)(A) (McKinney 1983); N.C. Gen. Stat. §7A-517(21) (Supp. 1988); N.D. Cent. Code §27-20-02-5(a) (Supp. 1987); Ohio Rev. Code Ann. §2151.03(C) (Anderson 1976); Okla. Stat. Ann. tit. 21, §845(B)(1) (West Supp. 1988); Or. Rev. Stat. §418.740(1)(e) (1987); Pa. Stat. Ann. tit. 11, §2203 (West Supp. 1988); R.I. Gen. Laws §40-11-3 (Supp. 1987); S.C. Code Ann. §20-7-490(c)(3) (Law Co-op. 1985); S.D. Codified Laws Ann. §26-8-6(4) (1984); Tenn. Code Ann. §37-1-102(10)(D) (Supp. 1987); Tex. Fam. Code Ann. §34.01 (West 1988); Utah Code Ann. §78-3a-2(17)(C) (1987); Vt. Stat. Ann. tit. 33, §682(3)(C) (Supp. 1987); Va. Code Ann. §16.1-228(2) (1988); Wash. Rev. Code Ann. §26.44.020(12) (West Supp. 1988); W. Va. Code §49-1-3(g)(1)(A) (1986); Wis. Stat. Ann. §48.981(1)(d) (West 1987); Wyo. Stat. §14-6-201(a)(xvi)(A) (1986).

The same is true of other jurisdictions: Am. Samoa Code Ann. §45.2001(a)(1)(C) (1986); Guam Gov't Code §9120.20(c)(3) (Supp. 1970); P.R. Laws Ann. tit. 8, §404(b) (Supp. 1987); and V.I. Code Ann. tit. 5, §2502(20) (Supp. 1987).

[2] See chap. 7 for a comprehensive discussion of the Child Abuse Amendments of 1984.

[3] Such a perception was also a motive for efforts by the executive branch of the Federal Government to attempt special measures under §504 of the Rehabilitation Act of 1973. See chap. 6.

Gerry persuaded a judge to take a novel course: to issue an order requiring that the child be brought before a court. In the court proceeding, 8-year-old Mary Ellen testified that she was beaten with a whip almost daily, was given no bed or shoes, was never permitted outside except in the yard at night, and was never allowed to play with other children. She was never kissed or caressed. Based on that testimony, the judge ordered her removed from the home and allowed Mrs. Wheeler to assume her guardianship.[5] This incident led Gerry to found the New York Society for the Prevention of Cruelty to Children (NYSPCC) in 1875.

The first child neglect statutes were relatively simple and tended to cover merely the failure of parents to provide for their children's upkeep. The coverage of the laws was gradually enlarged. By the end of the 1880s, for example, the New York statute was broad enough to protect children from neglect in the provision of food, clothing, sanitation, and medicine.[6]

In 1922 New York was among the first States to adopt a statute empowering courts to order that medical or surgical care be furnished to a child.[7] Applying that statute two decades later, a court observed:

> It is doubtful that under the common law, the courts had the powers now conferred on them, to order treatment for children to the extent even of a surgical operation or to require of parents to do that which is promotive of the interests and is protective of the rights of a child. We have emerged from that period in. . .history. . ., and left behind its prejudices, biases and limitations. . . .[8]

In current law, State intervention to ensure medical care for nondisabled children, even over parental objection, is commonplace. Although recognition and great deference is given to parental authority,[9] parents do not have unbridled control over their children. Their rights, whether rooted in the Constitution or in a basic public policy, may be limited or terminated, particularly when they affect their children's life and death.[10] "[T]he family itself is not beyond regulation in the public interest."[11] Civil government may act to "guard the general interest in youth's well being, the state as *parens patriae* may restrict the parent's control. . . ."[12]

Parens patriae is the legal doctrine which provides that the state has the authority, in proper circumstances, to intervene in the normal parent-child relationship for the protection of the child. The doctrine is largely composed of common law, distinguishing it from the provisions found in the child protection statutes. The conception of the doctrine of *parens patriae*, like that of other legal doctrines, has developed over the past few centuries as the common understanding of the role of law in society, as well as the cultural, economic, and social conditions, have changed.[13]

Under the modern understanding of that doctrine, the state can intervene to limit parental authority:[14]

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[4] Landau, *An Overview of Child Protection and the Abused and Neglected Child*, in The Abused and Neglected Child 7, 9 (1982). *See also* Bopp & Balch, *The Child Abuse Amendments of 1984 and Their Implementing Regulations*, 1 Issues in L. & Med. 91, 92 (1985).

[5] Landau, *supra* note 4, at 10.

[6] 1876 N.Y. Laws, ch. 122, §4; *see also* Cowley v. People, 83 N.Y. 464 (1881) (benevolent institution subject to statute declaring it a misdemeanor to permit a child to be endangered or injured in life or health).

[7] 1922 N.Y. Laws ch. 547, §§2 and 23.

[8] *In re* Rotkowitz, 175 Misc. 948, 25 N.Y.S. 624, 625 (1941). Under the common law, it was recognized that parents owed duties toward their children, as well as having rights over them. Blackstone, the preeminent legal commentator of his day, described the parent-child relationship and the responsibilities of the parent in this way:

> The duty of parents to provide for the *maintenance* of their children, is a principle of natural law; an obligation,. . .laid on them not only by nature herself, but by their own proper act, in bringing them into the world. . . .By begetting them, therefore, they have entered into a voluntary obligation, to endeavor, as far as in them lies, that the life which they have bestowed shall be supported and preserved. And thus the children will have a perfect *right* of receiving maintenance from the parents.

1 W. Blackstone Commentaries* 435.

[9] The Supreme Court observed in Wisconsin v. Yoder that:

> The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children. The primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition.

406 U.S. 205, 232 (1971). *See also* Pierce v. Society of Sisters, 268 U.S. 510, 535 (1925) ("The child is not the mere creature of the State; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations.").

[10] *See* Custody of A Minor, 375 Mass. 733, 379 N.E.2d 1053 (1978).

[11] Prince v. Massachusetts, 321 U.S. 158, 166 (1944).

[12] *Id.*

[13] *See generally* Custer, *The Origins of the Doctrine of Parens Patriae*, 27 Emory L. J. 195 (1978).

[14] *In re* N.H., 373 A.2d 851 (Vt. 1977).

> Like all authority. . .parental authority may be abused. Family privacy may become a cover for exploiting the inherent inequality between adult and child. Thus children who, by definition, are both physically and psychologically at risk may sometimes be placed at further risk by the adult "caretakers" who are presumed to be essential to their well-being.[15]

Although primary authority is vested in the parent, that authority is restricted, or even abrogated in full, whenever that authority is abused. In the words of the highest court of Massachusetts, "Parental rights. . .do not clothe parents with life and death authority over their children."[16]

The most frequently encountered situations involving life-threatening conditions for nondisabled children have been cases in which parents have refused to authorize medical care because of their religious beliefs. Jehovah's Witnesses have provided a recurring example. The traditional view of Jehovah's Witnesses has been that blood transfusions are morally prohibited.[17] In the usual situation, the parents refuse to consent to a transfusion that is necessary for a child in need of an operation. The parents are brought to court, normally by the hospital, to compel a transfusion through the appointment of a guardian *ad litem* to consent to the necessary medical care. Court after court has found that the State has the authority to intervene and direct a blood transfusion when a child's life is in imminent danger, invoking the State's child neglect or abuse statute or the expanded doctrine of *parens patriae.*[18]

As stated by the Supreme Court:

> Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.[19]

Different Treatment of Children with Disabilities

The government's disposition changes when the child denied treatment is one who has a disability. Commentator Joseph Goldstein, who wrote in 1977 of the danger of abuse of parental authority that may "cover for exploiting the inherent inequality between adult and child,"[20] also wrote: [I]t must be left to the parents to decide, for example, whether their congenitally malformed newborn with an ascertainable neurologic deficiency and highly predictable mental retardation, should be provided with treatment which may avoid death, but which offers no chance of cure—no opportunity, in terms of societal consensus, for a life worth living or a life of relatively normal healthy growth.[21]

In 1984 the Minnesota Supreme Court explicitly based its support for denial of treatment on the degree of disability:

> [T]he few patients who have recovered consciousness after a prolonged period of unconsciousness were severely

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[15] Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*. 86 Yale L.J. 645, 647 (1977).

[16] Custody of a Minor, 379 N.E.2d at 1063.

[17] Jehovah's Witnesses' objections are based upon their understanding of biblical passages directly prohibiting eating blood, which they regard as equivalent to a transfusion. *See, e.g., Gen.* 9:3–6; *Lev.* 7:26–27; 17:10–14; *Det.* 12:23–25.

[18] *In re* Clark, 21 Ohio Op. 2d 86, 185 N.E.2d 128, 129 (1962) ("When a child's right to live and his parent's religious belief collide, the former is paramount and the religious doctrine must give way."). *See also In re* Pogue, No. M-18-74 (Super. Ct. D.C., Nov. 11, 1974); People *ex rel.* Wallace v. Labrenz, 411 Ill. 618, 104 N.E.2d 769 (1952), *cert. denied*, 344 U.S. 824 (1952); Morrison v. State, 252 S.W.2d 97 (Mo. App. 1952); State v. Perricone, 37 N.J. 463, 181 A.2d 751, *cert. denied*, 371 U.S. 890 (1962); Muhlenberg Hosp. v. Patterson, 128 N.J. Super. 498, 320 A.2d 518 (1974); Hoener v. Bertinato, 67 N.J. Super. 517, 171 A.2d 140 (1961); Sampson v. Taylor, 29 N.Y.2d 900, 278 N.E.2d 918 (1972); Santos v. Goldstein, 16 App. Div. 2d 755, 227 N.Y.S.2d 450, *appeal dismissed*, 12 N.Y.S.2d 672, 185 N.E.2d 904 (1962); Application of Brooklyn Hosp., 45 Misc.2d 914, 258 N.Y.S.2d 621 (1965); *In re* Green, 448 Pa. 338, 292 A.2d 387 (1972), *later appeal*, 452 Pa. 373, 307 A.2d 279 (1973); Jehovah's Witnesses v. King County Hosp., 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968).

[19] Prince v. Massachusetts, 321 U.S. 158, 170 (1940). For a child protection system to be effective, the system must become aware of cases of abuse and neglect. In the 1960s, this need led to the adoption of laws requiring specified individuals to report suspected cases to the appropriate State agency. Enactment of such laws was proposed by the Children's Bureau in 1963. U.S. Children's Bureau, *The Abused Child: Principles and Suggested Language for Legislation on Reporting of the Physically Abused Child* (1963) *as cited in* Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 Hastings L. J. 765, 794 (1986). These principles were adopted swiftly: all States enacted mandatory reporting laws within 4 years. Fraser, *A Glance at the Past, A Gaze at the Present, A Glimpse at the Future: A Critical Analysis of the Development of Child Abuse Reporting Statutes*, 54 Chi.[-]Kent L. Rev. 641 (1978). Although the wording of such statutes varies, it normally requires that physicians, other health care providers, school personnel, social workers, and others report to the proper agencies if they suspect any neglect. Some States provide that everyone is obligated to report any suspected neglect. *See, e.g.*, N.J. Stat. Ann. §9:6–8.10 (West Supp. 1988). Reporting is frequently obligatory even if the individual receives information in a confidential capacity. The penalty for failure to report varies from a small fine to incarceration. Smith & Meyer, *Child Abuse Reporting Laws and Psychotherapy: A Time for Reconsideration*, 7 International J. L. & Psychiatry 351 (1984).

[20] Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 Yale L.J. 645, 647 (1977).

[21] *Id.* at 655-56.

> disabled. The degree of permanent damage varied but commonly included inability to speak or see, permanent distortion of the limbs, and paralysis. Being returned to such a state would be regarded as of very limited benefit by most patients; it may even be considered harmful if a particular patient would have refused treatments expected to produce this outcome. Thus, even the extremely small likelihood of "recovery" cannot be equated with returning to a normal or relatively well functioned state.[22]

The trial court judge who decided the Bloomington, Indiana, Infant Doe case[23] later made explicit that it was the child's disability, Down syndrome, that was the ground for his ruling that the parental denial of lifesaving treatment should not be disturbed. In his reply to a correspondent who questioned him about the case, he wrote:

> [E]ven at common law the right of the parents to autonomy over their children was not absolute and the State could intervene by way of the Court, acting as *parens patriae,* to protect minors and incompetents whose guardians were acting to the clear detriment of the ward. Today, parental autonomy is still favored, but of paramount concern, in case law and by statute, is the best interest of the child. A child is no longer merely a property right. Now the parent-child relationship is more in the nature of a trust, subject to the well-being of the child as perceived by the Court. . . .
>
> The State's role in protecting the welfare of the child becomes more complicated in a situation as that of the "Infant Doe" case. To say that parents are neglectful implies that the State or society knows what is best for the child. In the "Infant Doe" case, it could not be said that the parents were not acting in the best interests of the child, even though other parents might have acted differently. It is a harsh view that no life is preferable to life, but the great weight of the medical testimony at the hearing I conducted was that even if the proposed surgery was successful, the possibility of a minimally adequate quality of life was nonexistent.[24]

In the Baby Jane Doe case, the New York State courts upheld denial of treatment to a child born with spina bifida and other disabilities.[25] After her birth in Port Jefferson, New York, on October 11, 1983, her pediatric neurosurgeon arranged for her transfer to the University Hospital of the State University of New York at Stony Brook so she could receive lifesaving surgery.[26] Advice her parents received there, however, led them to opt against authorizing the surgery.[27] Based on information from a source within the hospital, an attorney who objected to the denial of treatment applied to a State court of general jurisdiction for the appointment of a guardian *ad litem* to argue that the court should order treatment, a request the court granted.[28]

The court conducted 2 days of hearings, taking testimony from physicians and the father of the child.[29] At their conclusion, the trial court judge ruled that surgery should be performed:

> The testimony of the witnesses before the Court indicated that the neurosurgeons' initial advice that surgery be performed was changed by Dr. Newman.
>
> . . . .
>
> . . .A parent, however, may not deprive a child of lifesaving treatment, however well intentioned. Even when the parents' decision to decline necessary treatment is based on Constitutional grounds such as religious beliefs, it must yield to the State's interests as [parens] patriae in protecting the health and welfare of the child. . . .There was instead an affirmative answer to the question, is there imminent danger of infection, and there was testimony indicating that the presence of infection would lead to death, and that in the Court's view the testimony further provided that by correcting the myelomeningocele condition, that this would significantly reduce the risk of infection.
>
> . . .It is clear. . .that the infant is in imminent danger, and that the infant has an independent right to survive; that right must be protected by the State acting the [parens] patriae, where a life is in jeopardy and the parents have elected to provide no surgical care. . . .[30]

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[22] *In re* Conservatorship of Torres, 357 N.W.2d 332, 338 (Minn. 1984). Although the case related to denial of treatment to an older person who was unconscious, it revealed an attitude toward disability relevant to a judicial perspective on denial of treatment to children with disabilities. The court also considered as relevant the cost associated with disability: "[L]ong-term treatment commonly imposes severe financial and emotional burdens on a patient's family, people whose welfare most patients before they lost consciousness, placed a high value on." *Id.* at 339.

[23] See chap. 1 and text accompanying notes 16–27.

[24] Baker, *June 8, 1982 Letter of Judge John Baker to Anonymous Person,* 2 Issues in L. & Med. 81, 82 (1986).

[25] See chap. 3, text accompanying notes 54–72, and chap. 6, text accompanying notes 89–107.

[26] United States v. Univ. Hosp., State Univ. of New York at Stony Brook, 729 F.2d 144, 146 (2d Cir. 1984).

[27] Horan & Balch, *Infant Doe and Baby Jane Doe: Medical Treatment of the Handicapped Newborn,* 52 Linacre Q. 45, 53 (1985).

[28] *Id.*

[29] Transcript, People *ex rel.* Washburn v. Stony Brook Hosp., No. 83-19910 (N.Y. Sup. Ct. Oct. 19, 1983) (available in files of the U.S. Commission on Civil Rights).

[30] *Id.* at 229, 236–38.

This decision, however, was promptly overturned by an intermediate appellate court,[31] and when that ruling was appealed to the state's highest court, the New York Court of Appeals, it held that the trial court had been without authority to entertain the case at all and affirmed the appellate division's dismissal. The court said:

> There are overtones to this proceeding which we find distressing. Confronted with the anguish of the birth of a child with severe physical disorders, these parents, in consequence of judicial procedures for which there is no precedent or authority, have been subjected in the last two weeks to litigation through all three levels of our State's court system. We find no justification for resort to or entertainment of these proceedings.[32]

There have been other cases in which State courts have upheld denial of lifesaving treatment to children on the basis of disability,[33] as well as cases in which State courts have prevented the withholding of such treatment from children with disabilities.[34] The key point is that while State courts in the contemporary era have invariably overridden parental decisions to deny treatment clearly necessary to preserve the lives of their nondisabled children, prior to the adoption of the Child Abuse Amendments of 1984, they had at best a mixed record in doing so when the children had disabilities.

Conclusion

In popular debate, the question whether children with disabilities should be denied lifesaving treatment has frequently been couched as though the issue were whether the government should intrude into matters of parental discretion. In fact, however, for decades the universally accepted law has been that when parents make treatment decisions that will undebatably lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating provision of lifesaving medical care. It is only when the children have disabilities that the claim of parental autonomy is given serious sympathetic consideration.

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[31] Weber, Guardian *ad litem* for Baby Jane Doe v. Stony Brook Hosp., No. 3467E (N.Y. App. Div. Oct. 21, 1983).

[32] *In re* Weber v. Stony Brook Hosp., 60 N.Y.2d 208, 469 N.Y.S.2d 63, 456 N.E.2d 1186, 1188 (1983).

[33] *See In re* Barry, 445 So.2d 365 (Fla. App. 1984), *cert. denied*, 464 U.S. 1026 (1985); *In re* L.H.R., 253 Ga. 439, 321 S.E.2d 716 (1984); and *In re* P.V.W., 424 So.2d 1015 (La. 1982).

[34] *See* Maine Medical Center v. Houle, Civ. No. 74-145 (Me. Super. Ct., Feb. 14, 1974); and *In re* Cicero, 101 Misc.2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979).

Chapter 6

The Rehabilitation Act of 1973

The history of efforts by the Federal Government to prevent medical discrimination against people with disabilities, particularly children, is closely interwoven with section 504 of the Rehabilitation Act of 1973.[1] Soon after the April 1982 Bloomington Infant Doe case brought public attention to the issue of denying treatment to children with disabilities, the Department of Health and Human Services (HHS) relied on section 504 as the basis for a written warning to hospitals throughout the country that discriminatory denial of treatment on the basis of handicap was illegal. In March 1983, HHS issued an "Interim Final Rule" requiring hospitals to post notices giving the telephone number of a 24-hour hotline for reporting suspected 504 violations. This poster rule evoked heated reaction.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research and the American Academy of Pediatrics, joined by other medical organizations, condemned the regulation. They argued that the use of hospital-based ethics committees was preferable to Federal involvement in treatment decisionmaking. The American Academy of Pediatrics sued HHS and convinced a Federal district court to strike down the regulation on the ground that the procedures used to issue it had not complied with those mandated by administrative law.

HHS then published a substantially similar rule as a proposed regulation in July 1983, inviting public comment. While HHS was analyzing that comment and meeting with medical and disability groups seeking a compromise, the New York Baby Jane Doe case arose in October 1983. Under the authority of section 504, HHS sought Baby Jane Doe's medical records and, when the hospital refused to provide them, took it to court. But HHS lost in both the district court and the Second Circuit Court of Appeals, with the latter ruling in February 1984 that section 504 had no application to medical treatment decisions regarding newborn children with disabilities.

Meanwhile, in January 1984, HHS had reissued a modified form of its poster regulation as a Final Rule. The American Medical Association and other medical organizations promptly challenged it in court as unjustified by section 504. Relying on the holding in the Baby Jane Doe case, both a district court and the Second Circuit Court of Appeals struck down the mandatory sections of the Final Rule. In June 1986, the Supreme Court affirmed in a 5-3 vote. However, an opinion explaining the affirmation was joined only by a plurality of the Court, and it addressed much narrower grounds than had the Second Circuit, leaving important issues concerning the application of section 504 to denial of treatment on the basis of handicap unresolved.

This chapter details these events and analyzes the legal issues at stake in the controversy over the applicability of section 504 to the discriminatory denial of medical treatment to children with disabilities.

Enactment of Section 504 of the Rehabilitation Act

Section 504 provides:

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[1] 29 U.S.C.A. §794 (West Supp. 1988).

> No otherwise qualified handicapped individual in the United States. . .shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . .[3]

Robert Scotch, who has written a history of the provision's crafting and enactment, notes: "Section 504. . .has been hailed as the first major civil rights legislation for disabled people. In contrast to earlier legislation that provides or extends benefits to disabled persons, it establishes full social participation as a civil right and represents a transformation of federal disability policy."[3] Modeled on legislation prohibiting race and sex discrimination by recipients of Federal financial assistance, section 504 may be enforced not only by cutting off such assistance but also through suits for injunctive relief by the Attorney General[4] and by aggrieved private individuals.[5]

Section 504 was derived from companion bills introduced by Senator Hubert Humphrey and Representative Charles Vanik.[6] "[T]he treatment and regard for the rights of handicapped citizens in our country is one of America's shameful oversights," Representative Vanik said in the speech with which he introduced the bill.[7] He referred to the "100,000 babies [who] are born with defects" each year. Referring to older citizens with disabilities, he condemned "confinement without treatment" and "unexplained deaths."[8] In a speech introducing his bill, Senator Hubert Humphrey said it would afford people with disabilities the "right to health."[9]

Later, to demonstrate a need for the legislation, Humphrey placed in the *Congressional Record* articles criticizing medical professionals for devaluing children with disabilities. One article referred to parents who "spoke angrily about pediatricians and purported experts in the field of retardation—the professionals who know pathetically little about the unused potential of retarded children and who continually discourage and delude parents."[10] One parent said, "There was so much willingness to eliminate the child, because they did not consider him a productive member of society. . . ." The article concluded that many parents of children with disabilities have a "deep anger" at a "system which regularly has written off certain categories of handicapped children, their children, as hopeless."[11]

It was in response to concerns such as these that the Senate committee report on the Rehabilitation Act of 1973 specifically stated that section 504's coverage was to include discrimination in "health services."[12]

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[3] 29 U.S.C.A. §794 (West Supp. 1988). For purposes of §794 handicapped individual is defined as:

> any individual who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.

29 U.S.C.A. §706(8)(B) (West Supp. 1988).

[3] R. Scotch, From Good Will to Civil Rights 3 (1984). The material that follows in this section relies heavily on National Legal Center for the Medically Dependent & Disabled, The Medical Treatment Rights of Children with Disabilities §2.03 at 2:9–2:10 (J. Bopp ed. 1987).

[4] Section 504 may be enforced by "any other means authorized by law, which includes suits by the Attorney General." 42 U.S.C. § 2000d-1 (1982); *see* United States v. Marion County School Dist., 625 F.2d 607, 611–12 (5th Cir. 1980), *cert. denied*, 451 U.S. 910 (1981).

[5] Consolidated Rail Corp. v. Darrone, 465 U.S. 624 (1984).

[6] The Supreme Court has emphasized the importance of this history: "[T]he intent with which Congressman Vanik and Senator Humphrey crafted the predecessor to §504 is a primary signpost on the road toward interpreting the legislative history of §504." Alexander v. Choate, 469 U.S. 287, 296 n.13 (1985).

[7] 117 Cong. Rec. 45,974 (1971) (statement of Representative Vanik).

[8] *Id.*

[9] 118 Cong. Rec. 525 (1972).

[10] 118 Cong. Rec. 9,499, 9,500 (1972).

[11] *Id.*

[12] S. Rep. No. 1297, 93rd Cong., 2d Sess. 38 (1974). In 1977 the Department of Health, Education, and Welfare (the predecessor to the Department of Health and Human Services) took the position that section 504 prohibits discrimination in the provision of medical treatment, although it does not create new entitlements for what was not previously provided to anyone:

> [A] burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.

45 C.F.R. Part 84, App. A para. 36 (1987). The Department thus took the position that section 504 did not mean that psychiatric patients have a right to receive treatment for the psychiatric problem for which they have been involuntarily committed or else be released. 41 Fed. Reg. 29548, 29559 (1976). Although this position was later cited for the proposition that the Department's view had been that section 504 does not authorize regulations dealing with rights to receive treatment, United States v. Univ. Hosp., 729 F.2d 144, 152 (2d Cir. 1984), Martin Gerry, former Director of the Office for Civil Rights of HHS during the development of the initial implementing regulations to section 504, explained that civil rights laws, including section 504, have been routinely applied to health care providers who receive Federal financial assistance:

> The direct application of federal civil rights laws to the operation of hospitals and other health care providers which receive Federal financial assistance was first established in 1964. The Final Regulation implementing Title VI of the Civil Rights Act of 1964, issued by the Department of Health, Education and Welfare in December 11 of the same year. . .prohibits discrimination on the basis of race, color or national origin in the operation of health care facilities

In May 1977, under the compulsion of a court order,[13] the Department of Health, Education, and Welfare (the predecessor of HHS) issued a regulation generally implementing section 504, much of which is still in effect. The Supplementary Information published with the 1977 regulation noted that "there is overwhelming evidence that in the past handicapped persons have been excluded from programs entirely or denied equal treatment, simply because they are handicapped."[14]

The regulation defines a "qualified handicapped person," for contexts other than employment or education, as "a handicapped person who meets the essential eligibility requirements for the receipt of such services."[15] It prohibited the providing of different services or benefits to qualified handicapped persons unless necessary to ensure that the services or benefits were as effective as those provided to nonhandicapped persons.[16] Indeed, a recipient of Federal funds must afford a qualified person with a disability a benefit or service that is as effective as that provided to nonhandicapped persons.[17] The regulation also proscribed the use of criteria or methods of administration having the purpose or effect of substantially impairing the accomplishment of program objectives for qualified individuals with a disability.[18]

Resort to Section 504 in the Aftermath of the Bloomington Infant Doe Case

The highly publicized Bloomington Infant Doe case in April of 1982 led to considerable public and press criticism of the denial of treatment that resulted in the child's death.[19] Reacting to the case and the widespread negative response to it, President Reagan on April 30, 1982, sent a memorandum to the Attorney General and Secretary of HHS concerning the enforcement of Federal laws prohibiting discrimination against individuals with a disability.[20] The memorandum required HHS to issue an explanation to health care providers of section 504's applicability to the denial of treatment to newborn children with a disability. HHS was also to enforce section 504 and other appropriate Federal laws to prevent the withholding of potentially lifesaving treatment from children with a disability that would normally be provided to children without a disability. The Attorney General was directed to report on "the possible application of Federal constitutional and statutory remedies in appropriate circumstances to prevent the withholding from the handicapped of potentially lifesaving treatment that would be given as a matter of course to those who are not handicapped."[21]

Accordingly, on May 18, 1982, the Office for Civil Rights of the Department of Health and Human Services sent hospitals receiving Federal financial assistance a Notice to Health Care Providers which indicated that it was unlawful to deny nutrition or medical or surgical treatment to an infant with a disability if the denial was based upon the existence of a handicap and the handicap did not render treatment or nutritional sustenance medically contraindicated.[22] Reflecting a concern that hospitals or their staff might attempt to do indirectly what could not lawfully be done directly, the notice stated that hospital "[c]ounseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under Section 504."[23]

In December 1982, internal guidelines for investigating complaints of discriminatory denial of treatment were sent to the regional divisions of the HHS Office for Civil Rights.[24] Between the death of

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> receiving funds under a wide variety of federal health care programs. . . .Civil rights obligations imposed upon hospitals and other health service providers by federal civil rights laws are neither new nor secret.

M. Gerry, The Right of Handicapped Infants to Receive Beneficial Medical Treatment: The Responsibilities of Health Care Providers Under Section 504 of the Rehabilitation Act of 1973, Statement Submitted to the 1985 Hearings of the United States Commission on Civil Rights on the Protection of Handicapped Newborns 27–28 (July 12, 1985) (available in the files of the U.S. Commission on Civil Rights).

[13] Cherry v. Mathews, 419 F. Supp. 922 (D.D.C. 1976).

[14] *Part 84—Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting From Federal Financial Assistance,* 42 Fed. Reg. 22,676, 22,676 (1977).

[15] 45 C.F.R. §84.3(k)(4) (1987).

[16] *Id.* §84.4(b)(1)(iv) (1987).

[17] *Id.* §84.4(b)(1)(ii) (1987).

[18] *Id.* §84.4(b)(4) (1987).

[19] See chap. 1 and text accompanying notes 16–27 for a description of the case.

[20] R. Reagan, President's Memorandum to the Attorney General and the Secretary of Health and Human Services, Enforcement of Federal Laws Prohibiting Discrimination Against the Handicapped (Apr. 30, 1982), *noted in* S. Rep. No. 246, 98th Cong., 2d Sess. 6, portions *reprinted in* 1984 U.S. Code Cong. & Admin. News 2918.

[21] *Id.*

[22] *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers,* 47 Fed. Reg. 26,027 (1982).

[23] *Id.*

[24] Memorandum from Nathan D. Dick, Deputy Director, Office of Program Operations, HHS, to Regional Directors, Office for

Bloomington's Infant Doe in April 1982 and March 7, 1983, HHS received 11 complaints of discriminatory denial of lifesaving medical treatment to newborn children with disabilities.[25] HHS conducted investigations in 9 of the 11 instances, including 5 onsite investigations.[26]

The "Interim Final Rule" of March 1983

On March 7, 1983, HHS issued a new regulation that was to provoke a storm of controversy.[27] It was the first of three versions of regulations or proposed regulations under authority of section 504 that explicitly and specifically addressed the withholding of medical treatment from children with disabilities.[28]

The Supplementary Information published with the Interim Final Rule gave as its purpose to "acquire timely information concerning violations of Section 504 that are directed against handicapped infants, and to *save the life of the infant.*"[29] Expressing concern that individuals with knowledge of actions violating section 504 did not have adequate opportunity to give immediate notice to governmental authorities, HHS designed the Interim Final Rule to increase public knowledge of the law and the manner of bringing suspected violations to the attention of HHS, and to increase the ability of HHS to investigate alleged violations promptly.

HHS wrote that the rule had become necessary because events "of the past several years suggest that handicapped infants have died from denial of food in federally assisted programs."[30] The Department said that although the extent of discriminatory denial of treatment was unknown, "for even a single infant to die due to lack of an adequate notice and complaint procedure is unacceptable."[31]

The May 1982 Notice to Health Care Providers, the Supplementary Information stated, "explained what is already clear from the language of Section 504 and [its existing] regulations. . .: The discriminatory failure of a federally assisted health care provider to feed a handicapped infant, or to provide medical treatment essential to correct a life-threatening condition, can constitute a violation of Section 504."[32] Therefore, HHS wrote, the Interim Final Rule was not intended to create any variance in the substantive obligations of health care providers "previously set forth in the statutory language of Section 504, in the implementing regulations, and in the Notice to Health Care Providers."[33] Instead:

> The interim final rule sets forth procedural specifications designed: (1) To specify a notice and complaint procedure, within the context of the existing regulations, and (2) to modify existing regulations to recognize the exigent circumstances that may exist when a handicapped infant is denied food or other necessary medical care.[34]

The Interim Final Rule required infant health service facilities to display posters in conspicuous places in nurseries and in delivery, maternity, and pediatric wards. The notices were to state that discriminatory failure to feed and care for handicapped infants in the facility is prohibited by Federal law, that anyone having knowledge of an infant being denied food or customary medical care should contact the HHS hotline or the State child protec-

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Civil Rights, HHS Directive OPO-83-1-8 (Dec. 14, 1982) (available in files of U.S. Commission on Civil Rights).

[25] *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants,* 49 Fed. Reg. 1,622, 1,646–47 (1984) [hereinafter Final Rule (504)].

[26] *Id.* In one of the two remaining cases in which no investigations were undertaken, HHS "postponed" investigation at the request of local prosecutors. In the other case, HHS reported having conducted an "inquiry," though not an investigation. On the basis of the "inquiry," HHS closed the case, finding no violation. For further discussion of investigations conducted by the HHS Office for Civil Rights, see chap. 12, text accompanying notes 3–11.

[27] *Nondiscrimination on the Basis of Handicap, Interim Final Rule,* 46 Fed. Reg. 9630 (1983).

[28] The number and variety of Federal regulations related to "Baby Doe" that have been proposed or issued at various times can be confusing. The regulations promulgated under section 504, discussed in this chapter, must be distinguished from the regulations promulgated under the Child Abuse Amendments of 1984, discussed in the next chapter. For convenience, a chronology of the relevant laws, regulations, and court decisions challenging them may be helpful:

1973: Passage of Rehabilitation Act, including section 504
1977: Basic section 504 regulations issued
Mar. 7, 1983: Interim Final Rules (504) issued
Apr. 14, 1983: Judge Gesell strikes down Interim Final Rules
July 5, 1983: Proposed Rules (504) issued for comment
Jan. 12, 1984: Final Rules (504) promulgated
Feb. 23, 1984: In Baby Jane Doe case, Second Circuit holds 504 inapplicable to medical treatment decisions
June 11, 1984: Final Rules (504) enjoined by Federal district court
Oct. 9, 1984: Child Abuse Amendments of 1984 (CAA) signed into law
Dec. 10, 1984: Proposed Rules (CAA) issued for comment
Apr. 15, 1985: Final Rules (CAA) promulgated
Oct. 9, 1985: CAA and Final Rules (CAA) go into effect
June 9, 1986: U.S. Supreme Court holds mandatory portions of Final Rules (504) unjustified by administrative record

[29] *Nondiscrimination on the Basis of Handicap, Interim Final Rule,* 48 Fed. Reg. 9,630, 9,630 (1983) (emphasis in original).

[30] *Id.* at 9,631.

[31] *Id.*

[32] *Id.* at 9,630.

[33] *Id.*

[34] *Id.*

tive agency, and that the failure to feed and care for infants might violate State law.[35]

Normally, HHS is required to wait 10 days from the time that the Secretary notifies the suspected violator of a failure to comply with section 504 before legal action is initiated. The Interim Final Rule provided for a waiver of this waiting period whenever, in the judgment of HHS, immediate access was necessary to preserve the life or health of an infant with a disability.[36] It also allowed HHS immediate access to business records outside normal business hours when necessary to protect the infant's life or health.[37]

Although it set up a 24-hour hotline to receive reports of suspected denial of treatment, HHS indicated that it intended to rely heavily on the voluntary cooperation of State and local agencies closest to the scene, which could provide "speedy investigation of life-threatening abuse and neglect."[38] State child protective agencies would be informed of cases of which HHS became aware. When the State "expeditiously and effectively investigated" the cases, additional Federal involvement would be unnecessary although HHS would hold itself open for whatever assistance was desired.[39]

President's Commission Report

In March 1983—the same month the Interim Final Rule was promulgated—the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issued a report entitled *Deciding to Forego Life-Sustaining Treatment.*[40] Although HHS would later cite with favor some of the statements in the report,[41] not only did the President's Commission Report specifically criticize the HHS regulation,[42] but its general perspective significantly differed from that of HHS. The President's Commission believed that "seriously erroneous decisions about the treatment of newborns. . .appear to be very rare."[43] Nevertheless, it acknowledged three shortcomings in decisionmaking about infants with a disability: "[first,] appropriate information may not be communicated to all those involved in the decision; [second,] professionals as well as parents do not at times understand the bases of a decision to treat or not to treat; and [third,] actions can be taken without the informed approval of parents or other surrogates."[44]

The President's Commission divided circumstances in which a child with a disability has life-threatening conditions into three categories: "(1) a treatment is available that would clearly benefit the infant, (2) all treatment is expected to be futile, or (3) the probable benefits to an infant from different choices are quite uncertain."[45] The actions it recommended are shown in table 6.1.

Under the proposal of the President's Commission, both when the physician's assessment is "unclear" and when the joint decision of parents and physician is to forego treatment, the assessment would be reviewed by "intra-institutional mechanisms and possibly thereafter by the court."[46] By "intra-institutional mechanisms" the President's

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[35] The poster was to read:

> **DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW**
>
> Section 504 of the Rehabilitation Act of 1973 states that no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.
>
> *Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary care should immediately contact:*
>
> Handicapped Infant Hotline
> U.S. Department of Heath and Human Services
> Washington, D.C. 20201
> Phone 800——— (Available 24 hours a day)
> In the City of Washington, D.C.—863- 00 (TTY capability)
> *or*
> Your State Child Protective Agency
>
> Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.
>
> Identity of callers will be held confidential.
>
> Failure to feed and care for infants may also violate the criminal and civil laws of your State.

HHS provided the sign, and the only permissible alteration was the addition of the agency's name and its address and telephone number. *Id.* at 9,631-32.

[36] *Id.* at 9,630.

[37] *Id.*

[38] *Id.* at 9,631.

[39] *Id.*

[40] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment (1983) [hereinafter *President's Commission Report*].

[41] *See, e.g., Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants, Final Rules,* 49 Fed. Reg. 1,622, 1,622 (1984).

[42] *President's Commission Report, supra* note 40, 225-26 & n.95.

[43] *Id.* at 208-09.

[44] *Id.* at 209.

[45] *Id.* at 217.

[46] *Id.*

TABLE 6.1

Physician's assessment of treatment options*	Parents prefer to accept treatment**	Parents prefer to forego treatment**
Clearly beneficial	Provide treatment	Provide treatment during review process
Ambiguous or uncertain	Provide treatment	Forego treatment
Futile	Provide treatment unless provider declines to do so	Forego treatment

*The assessment of the value to the infant of the treatments available will initially be by the attending physician. Both when this assessment is unclear and when the joint decision between parents and physician is to forego treatment, this assessment would be reviewed by intra-institutional mechanisms and possibly thereafter by court.

**The choice made by the infant's parents or other duly authorized surrogate who has adequate decisionmaking capacity and has been adequately informed, based on their assessment of the infant's best interests.

Source: President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life Sustaining Treatment (1983), 218, table 1 (certain footnotes omitted).

Commission primarily meant hospital ethics committees.[47]

When treatment is "clearly beneficial," the President's Commission wrote, "[p]arents should be able to choose among alternative treatments with similarly beneficial results and among providers, but not to reject treatment that is reliably expected to benefit a seriously ill newborn substantially, as is usually true if life can be saved."[48] The President's Commission emphasized that this is a "very strict standard" because:

> [I]t excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants. The Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.[49]

The President's Commission specifically pointed to infants with Down syndrome, indicating that this disability, in itself, does "not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract."[50] The President's Commission thus implicitly criticized the result in the Bloomington Infant Doe case.

On the other end of the treatment spectrum, the "clearly futile" category, the President's Commission took the position that it is unnecessary to provide treatment that would only maintain life for a short period of time:

> When there is no therapy that can benefit an infant, as in anencephaly or certain severe cardiac deformities, a decision by surrogates and providers not to try predictably futile endeavors is ethically and legally justifiable. Such therapies do not help the child, are sometimes painful for the infant (and probably distressing to the parents), and offer no reasonable probability of saving life for a substantial period. The moment of death. . .might be delayed for a short time—perhaps as long as a few weeks—by vigorous therapy.[51]

In such circumstances, however, the President's Commission said that the children are still owed "whatever relief from suffering and enhancement of life can be provided, including feeding, medication for pain, and sedation, as appropriate."[52]

The third category delineated by the President's Commission consisted of "ambiguous cases."

> Although for most seriously ill infants there will be either a clearly beneficial option or no beneficial therapeutic options at all, hard questions are raised by the smaller number for whom it is very difficult to assess whether the treatments available offer prospects of benefit—for example, a child with a debilitating and painful disease who might live with therapy, but only for a year or so, or a respirator-dependent premature infant whose long-term prognosis becomes bleaker with each passing day.[53]

While the section 504 approach adopted by HHS put emphasis on the substantive standards establishing what treatment must be provided, the approach adopted by the President's Commission emphasized the procedural standards establishing who should decide what treatment should be given. Rejecting both regular resort to the courts and the section 504 regulatory approach adopted by HHS, the President's Commission recommended instead a reliance on intra-institutional review. It suggested that hospitals should:

> have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants. . . .Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone. . . .Some cases may require only a medical consultation to confirm a diagnosis of an inevitably fatal condition. . . .In other cases, when the benefits of therapy are less clear, an "ethics committee" or similar body might be designated to review the decisionmaking process. This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases.[54]

Section 504 is directed against discrimination based on handicap. Thus, the measure of what treatment is required is what treatment would be provided to a similarly situated nonhandicapped individual. Since, for example, futile treatment that would merely prolong dying is not normally given to nonhandicapped terminally ill patients, section 504 would not require that it be provided to similarly situated individuals with handicaps.[55]

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[47] *Id.* at 227.

[48] *Id.* at 217-18.

[49] *Id.* at 219.

[50] *Id.* at 218-21.

[51] *Id.* at 219. The President's Commission's conclusion that treatment that merely prolongs dying should not be mandated by law has found few dissenters and is congruent with both HHS interpretations of section 504 and the Child Abuse Amendments of 1984.

[52] *Id.* at 220.

[53] *Id.*

[54] *Id.* at 227.

[55] *See* 45 C.F.R. Part 84 App. C(a)(2) (1987).

Essentially, HHS interpreted the substantive rule under section 504 to be that unless the handicap itself medically contraindicates the treatment (and thus renders the individual not "otherwise qualified" for the treatment), the handicap must be deemed irrelevant in treatment decisionmaking.[56]

The President's Commission approach could be said to have established substantive standards, since it divided cases into three categories. However, the descriptions of the categories were too generalized to provide much guidance for specific instances, with the meager exception of the Commission's condemnation of withholding of treatment solely on the basis of Down syndrome. The effect of the generalizations is that the formulae can be widely interpreted, leaving, at best, wide discretion in applying the principles. Although the basic notion of futility is defined with some clarity, the breadth and vagueness of the "clearly beneficial" and the "ambiguous" categories leave much room for differing judgments.

This lack of specificity reflected a deliberate choice by the President's Commission. It quoted with approval bioethicist Robert Veatch:

> The decision [to treat or not] must. . .include evaluation of the meaning of existence with varying impairments. Great variation exists about these essentially evaluative elements among parents, physicians, and policy makers.[57]

The report then stated:

> The Commission agrees that such criteria necessarily include value considerations. Supposedly objective criteria such as birth weight limits or checklists for severity of spina bifida have not been shown to improve the quality of decisionmaking in ambiguous and complex cases. Instead, their use seems to remove the weight of responsibility too readily from those who should have to face the value questions—parents and health care providers.[58]

The central themes embodied in the President's Commission report were to become the most widely reiterated grounds on which medical groups and others opposed the advocacy by disability groups of government action to protect the treatment rights of children with disabilities. These key points were repeatedly echoed in criticisms of the section 504 regulation and—later—the Child Abuse Amendments of 1984:

- Inappropriate treatment decisions, although they occur, do so rarely.
- Situations in which treatment decisions must be made are best broken into the three categories of clearly beneficial, ambiguous, and futile.
- Apart from saying treatment for children with Down syndrome is clearly beneficial, little definition can be given to distinguish the clearly beneficial from the ambiguous.
- Within these broad categories, discretion must be given to well-informed parents and physicians to make decisions in the best interests of children.
- Intra-institutional review, usually in the form of ethics committees, is the best check on possible abuses.
- Government agencies or courts should normally become involved only when an ethics committee considers that clearly beneficial treatment is being refused by adamant parents.

American Academy of Pediatrics v. Heckler

The HHS regulation was soon subject to more than rhetorical attack. The American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, and the Children's Hospital National Medical Center filed suit in the Federal District Court for the District of Columbia to invalidate it, contending that the Interim Final Rule was arbitrary and capricious, that HHS lacked the statutory authority to promulgate the rule, and that the rule impermissibly intruded into confidential relationships protected by the Constitution.[59] On April 14, 1983, Judge Gerhard Gesell invalidated the Interim Final Rule on procedural grounds, holding that the Interim Final Rule should have been published for public comment.[60]

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[56] *See infra* note 100 for a discussion of the situation in which the handicap is itself the source of the life-threatening condition to be treated.

[57] *President's Commission Report, supra* note 40, at 222, *quoting* R. Veatch, *The Technical Criteria Fallacy*, 7 Hastings Ctr. Rep. 15 (1977).

[58] *President's Commission Report, supra* note 40, at 223.

[59] Am. Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983).

[60] The Administrative Procedure Act requires that a general notice of proposed rulemaking be published in the Federal Register at least 30 days prior to the effective date. An agency must then give interested individuals the ability to participate in the rulemaking through submission of written data, views, or arguments. An agency need not adhere to these restrictions if either (i) the rules are interpretative (that is, non-binding), general statements of policy, or rules of organization, procedure or practice or (ii) the agency, for good cause, finds the notice and public procedure are impracticable, unnecessary or contrary to the public interest. 5 U.S.C.A. §553 (1977).

He also ruled that Secretary of Health and Human Services Margaret Heckler had insufficient material before her to consider relevant factors and assure rational consideration of the effect of the contemplated regulatory action.[61] Gesell also expressed considerable skepticism that section 504 was intended to apply to medical treatment decisions involving children with disabilities and suggested that, if it were, it might in at least some applications be an unconstitutional infringement on the right of privacy.[62]

Proposed 504 Rule, July 1983

HHS quickly moved to overcome the procedural objections that caused Judge Gesell to invalidate the Interim Final Rule. On July 5, 1983, HHS published a revised version of the earlier rule for public comment in the form of a "proposed rule."[63]

The Supplementary Information for the proposed rule addressed Gesell's criticisms of the Interim Final Rule. Finding nothing in the plain language of section 504 or its legislative history to indicate an intent that infants not be given the protection the statute affords those who are not infants, the preamble concluded that an infant with a disability is both an "individual" within the protection of section 504, and a "person" within the protection of its implementing regulation. A "qualified handicapped infant" was defined as one who could benefit medically from the treatment:

> Section 504 would hold that where an infant would not benefit medically from a particular treatment, the infant would not be "qualified" to receive the treatment; thus, its denial would not violate Section 504.[64]

HHS responded to Judge Gesell's concern that there was insufficient evidence of widespread denial of treatment to justify the rule by reviewing a number of cases and citing surveys indicating that denial of treatment was accepted by the majority of pediatricians.[65]

The proposed rule was substantially similar to the Interim Final Rule. In response to charges that the Interim Final Rule would lead to a plethora of unsubstantiated reports by janitors, visitors, and other members of the general public incompetent to make judgments about the adequacy of medical treatment, the proposed rule allowed the required poster to be placed only in nurses' stations, rather than in wards open to the public. It added a new provision relating to child protective services agencies receiving Federal financial assistance. They were required to develop procedures to ensure prompt processing of denial of treatment reports, with provisions for onsite investigations and the seeking of court orders to secure treatment. They were to notify the HHS Office for Civil Rights of reports received and the steps taken to investigate them.[66]

Judge Gesell rejected the government's argument that the Interim Final Rule was either procedural or interpretive, viewing the action as substantive because it provided for an "intrusive on-premises enforcement mechanism." *American Academy of Pediatrics*, 561 F. Supp. at 401. The good cause exception of §553 of the Administrative Procedure Act, the court noted, is narrowly construed and only reluctantly countenanced. *Id.* The government argued that the lives of the infants were at risk, and this required the expedited implementation of the regulations. Judge Gesell saw this as a slippery slope:

> Such an argument could as easily be used to justify immediate implementation of any sort of health or safety regulation, no matter how small the risk for the population at large or how long-standing the problem. There is no indication in this case of any dramatic change in circumstances that would constitute an emergency justifying shunting off public participation in the rulemaking.

Id.

[61] Among the factors Judge Gesell believed HHS should have considered were (i) the disruptive effects of the hotline; (ii) "the sudden descent of 'Baby Doe' squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment"; (iii) the interests of a child forcibly removed from a hospital if the parents refuse to consent to surgery; (iv) termination of Federal assistance to the hospital as a whole if a violation occurred; (iv) weighing of other factors against the malpractice and disciplinary risks that would be imposed upon doctors and hospitals; (v) whether the termination of painful procedures would be preferable when the prognosis is certain death; (vi) the means of funding the extensive care that would be required by the children whom the regulation saved and the allocation of scarce medical resources between defective newborns and other patients; and (vii) alternative means of protecting infants with a disability. *Id.* at 399–400.

[62] 561 F. Supp. at 403.

[63] *Nondiscrimination on the Basis of Handicap*, 48 Fed. Reg. 30,846 (proposed July 5, 1983).

[64] *Id.* In response to Judge Gesell's expressed concern that HHS had given inadequate consideration to whether the termination of painful procedures would be desirable for a child whose prognosis is certain death, the preamble stated:

> Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies. . .which merely temporarily prolong the process of dying of an infant born terminally [ill]. . . .Such medical decisions, by medical personnel and parents, concerning whether to treat, and if so, what form the treatment should take, are outside the scope of Section 504.

Id. at 30,846–47.

[65] *Id.* at 30,847–48.

[66] *Id.* at 30,851.

Final 504 Rule

HHS received nearly 17,000 comments on the proposed rule, of which 97.5 percent were favorable.[67] It also conducted intensive negotiations with medical organizations and disability rights advocacy groups.[68] Of particular importance in these discussions was the position of the American Academy of Pediatrics (AAP). In congruence with the President's Commission report, the AAP proposed:

> as an alternative to the proposed rule, that all hospitals, as a condition of participation in the Medicare program (not as a requirement of section 504) establish a review committee. Under this proposal. . .the committee would have three functions: (1) to develop hospital policies and guidelines for management of specific types of diagnoses; (2) to monitor adherence through retrospective record review; and (3) to review, on an emergency basis, specific cases when the withholding of life-sustaining treatment is being considered. When the committee disagreed with a parental or physician decision to withhold treatment, the case would be referred to the appropriate court or child protective agency, and treatment would be continued pending a decision.[69]

As a result of the negotiations, the HHS Final Rule, issued on January 12, 1984, was a compromise that incorporated features of the AAP proposal and made other modifications in the proposed rule; in return, the AAP agreed not to challenge the Final Rule.[70] HHS wrote: "These modifications are designed to establish a framework under which the substantial controversy that has attended the Department's efforts to strengthen enforcement of section 504 in this area can be replaced by a more cooperative effort involving the Federal Government, the medical community, private advocacy groups and state governments."[71]

Key components of the Final Rule were (1) its integration of a voluntary, modified form of ethics committees, to be called "Infant Care Review Committees"; (2) its modified poster requirement; (3) its requirements for State agencies; and (4) its provisions for expedited investigation and enforcement action.

The Final Rule encouraged, but did not require, hospitals to establish infant care review committees (ICRCs),[72] and it described the purpose, procedures, and composition of a model committee.[73] The differences between the AAP model and that in the Final Rule were intended to "underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504."[74]

> The Department does not seek to take over medical decisionmaking regarding health care for handicapped infants. HHS agrees that the best decisionmakers are generally the parents and the physicians directly involved. However, there is, and must be, a framework within which the decisionmakers, the parents and physicians, operate.
>
> That framework is established by laws. . . .includ[ing] section 504. . . .
>
> The fundamental issue involved in deciding whether review boards should be a substitute for enforcement of section 504 is whether the legal framework within which the decisionmaking parents and physicians are supposed to function (and generally do function) will be utilized. Under the proposal that review boards act in lieu of government, whether physicians or hospital review boards adhere to the principles of section 504 would be determined by those physicians and boards alone. . . .Whether they ever utilize the implementation schemes established by law to ensure that those principles are adhered to would also be decided by those parents, physicians, and review boards. . . .This alternative proposal simply does not provide sufficient safeguards that the requirements of section 504 will be met. . . .[I]t would not be justifiable for the Department to refrain from exercising a regulatory role to enforce the statute.
>
> . . .[A]lthough unacceptable as a substitute, review boards can be very valuable. . . .[A] committee that includes individuals with medical expertise and people with non-medical perspectives and that is guided by proper standards and protocols can be very helpful in bringing about informed, enlightened and fair decisionmaking. . . .[75]

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[67] Final Rule (504), *supra* note 25, at 1,623.

[68] Barringer, *Koop Acted as Midwife for New "Baby Doe" Rule*, Washington Post, Jan. 10, 1984, at A15, col. 3.

[69] Final Rule (504), *supra* note 25, at 1,623.

[70] Barringer, *supra* note 68, at A15, cols. 3–4. This agreement did not keep the AAP's fellow medical organizations, the American Medical Association and the American Hospital Association, from suing (successfully) to enjoin them. *See infra* note 109 and accompanying text.

[71] Final Rule (504), *supra* note 25, at 1,622.

[72] *Id.* at 1651. HHS noted that review boards were still untried, that enforcement of a requirement for such committees in the 7,000 hospitals in the country would be difficult, and that because the American Medical Association and other medical groups opposed any mandatory requirement, "there would likely be protracted legal proceedings challenging the regulation." *Id.* at 1,624.

[73] 45 C.F.R. §84.55(a) & (f) (1987). Infant care review committees, and the difference between their role as conceived by the President's Commission Report and AAP, on the one hand, and HHS, on the other hand, are discussed in chap. 11.

[74] Final Rule (504), *supra* note 25, at 1,625.

[75] *Id.* at 1624.

HHS agreed that when it investigated reports of discriminatory denial of treatment at a hospital, it would generally first consult with the hospital ICRC and delay investigating for 24 hours to receive information from the ICRC unless "other action is necessary to protect the life or health of a handicapped infant."[76] It encouraged State child protective services agencies to adopt similar guidelines for consulting with ICRCs.[77]

The Final Rule not only redrafted the original notice required to be posted in hospitals, but also gave hospitals the option of posting either of two alternative notices. A hospital with an internally adopted policy congruent with section 504 and with an internal review mechanism, including the opportunity to make an anonymous report free of retaliation, could post a notice with language designed to avoid suggesting that the hospital was an object of suspicion.[78] The notice could be posted in any location where medical professionals such as nurses could see it; it need not be posted where patients, visitors, or others could see it; and its size was reduced to 5 by 7 inches.[79]

The Final Rule established basic duties for State child protective services agencies receiving Federal financial assistance in dealing with reports to them of medical neglect of children with disabilities. Each such agency was obligated to establish and maintain procedures to ensure that the agency use its "full authority. . .to prevent instances of medical neglect of handicapped infants."[80] The procedures included requirements that health care providers report instances of known or suspected medical neglect on a "timely basis";[81] that a method be established by which the agency receives these reports;[82] that there be immediate review, and, where appropriate, onsite investigation, of such reports,[83] and provision for the protection of "medically neglected handicapped infants," including, if necessary, court orders to compel necessary nourishment and medical treatment.[84] Further, each State agency was to provide timely notification to HHS of every report of "suspected unlawful medical neglect of handicapped infants."[85]

As had its predecessors, the Final Rule authorized expedited access to hospital records when, in the judgment of HHS, immediate access was necessary to protect the life or health of an individual with a disability.[86] The Final Rule also eliminated the normal 10-day notice requirement when, in the judgment of the responsible HHS official, immediate action to effect compliance was necessary to protect the life or health of an individual with a disability.[87]

The expedited compliance provisions were designed to permit HHS to obtain a temporary restraining order to sustain the life of an infant in imminent danger of death.[88]

Effect of *University Hospital*

The underlying premise of the Final Rule was called into question by the Second Circuit's ruling in the Baby Jane Doe case on February 23, 1984.[89] Baby Jane Doe was born on October 11, 1983.[90] The final New York court ruling against requiring lifesaving operations to close her back lesion and install a shunt for her hydrocephalus came on October 28, 1983. On October 19, HHS had received a complaint under section 504 relating to the case.[91] After studying the evidence entered in the State court proceedings, which included the child's medical records from birth through October 19, the Surgeon General considered it necessary to obtain more recent medical records to determine if any violation of section 504 had occurred. The Surgeon General stated: "An appropriate determination concerning whether the current care of Infant Jane Doe is within the bounds of legitimate medical judgment, rather than based solely on a handicapping condition which is not a medical contraindication to surgical treatment, cannot be made without immediate access to. . .current medical records. . . ."[92] When repeated requests for the records by HHS were rebuffed, the Department of Justice filed suit in Federal district court for an injunction requiring the hospital to make them available.[93]

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[76] 45 C.F.R. Part 84 App. C(b)(2) (1987).

[77] 45 C.F.R. §84.55(c)(2) (1987).

[78] The notice read:

> **PRINCIPLES OF TREATMENT OF DISABLED INFANTS**
>
> It is the policy of this hospital, consistent with Federal law, that nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgements) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.
>
> This Federal law, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:
>
> [Identify designated hospital contact point and telephone number] or
>
> [Identify appropriate child protective services agency and telephone number] or
>
> U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day; TDD capability).
>
> The identity of callers will be held confidential. Retaliation by this hospital against any person for providing information about possible noncompliance is prohibited by this hospital and Federal regulations.

Id. §84.55(b)(3). The notice to be used in hospitals without such policies was essentially the same, but began "Federal law prohibits discrimination on the basis of handicap" and eliminated references to hospital policy. *Id.* §84.55(b)(4).

[79] Final Rule (504), *supra* note 25, at 1,626.

[80] *Id.* §84.55(c)(1).

[81] *Id.* §84.55(c)(1)(i).

[82] *Id.* §84.55(c)(1)(ii).

[83] *Id.* §84.55(c)(1)(iii).

[84] *Id.* §84.55(c)(1)(iv).

[85] *Id.* §84.55(c)(1)(v). The Supplementary Information made clear that this applied to decisions of parents. Final Rule (504), *supra* note 25, at 1,622.

[86] 45 C.F.R. §84.55(d).

[87] 45 C.F.R. §88.45(e).

[88] Final Rule (504), *supra* note 25, at 1,628.

[89] The case is also discussed in chap. 2 (text accompanying notes 14–15); chap. 3 (text accompanying notes 54–72); and chap. 5 (text accompanying notes 25–32).

[90] United States v. Univ. Hosp., 729 F.2d 144 (2d Cir. 1984).

Although acknowledging that University Hospital was a recipient of Federal financial assistance and subject to section 504, the district court entered summary judgment against the government, holding that the records already available established that the hospital had not engaged in discrimination prohibited by 504. The court found that "the papers submitted demonstrate conclusively that the decision of the parents to refuse consent to the surgical procedures was a reasonable one based on due consideration of the medical options available. . . ."[94]

The government appealed to the Second Circuit Court of Appeals. It maintained that the district court's ruling had the absurd effect of requiring HHS to make an advance evidentiary showing concerning the ultimate issue of unlawful conduct as a prior condition to securing the materials necessary to reach the determination whether unlawful conduct had occurred. The Second Circuit noted that "[a]n administrative agency is entitled to access to information 'not plainly incompetent or irrelevant to any lawful purpose of the [agency] in the discharge of [its] duties.'"[95] However, the Second Circuit concluded that the proper question was whether "the subject matter of the investigation is within the agency's statutory jurisdiction."[96]

The Second Circuit concluded it was not. After dismissing the regulatory history as "inconclusive,"[97] and holding that Baby Jane Doe was indeed a "handicapped individual" for purposes of section 504,[98] the court essentially argued that the language of the provision was not naturally adapted to the evaluation of medical treatment decisions. First, the court focused on the statute's requirement that such an individual be "otherwise qualified" for the benefits in question:

> [T]he phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning. In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents.[99]

Second, the court wrote that medical decisionmaking is too complex to be analyzed in terms of "discrimination":

> Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". . . .Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a "bona fide medical judgment," however that phrase might be defined.[100]

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[91] *Id.* at 146.

[92] *Quoted in id.*

[93] HHS relied upon 45 C.F.R. §80.6(c):

> Each recipient [of Federal funds] shall permit access by the responsible Department official or his designee during normal business hours to such of its books, records, accounts and other sources of information, and its facilities as may be pertinent to ascertain compliance. . . .Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance. . . .

[94] United States v. Univ. Hosp., 575 F. Supp. 607, 614–15 (E.D.N.Y. 1983), *aff'd* 729 F.2d 144 (2d Cir. 1984).

[95] *University Hospital,* 729 F.2d at 149, *quoting* Endicott Johnson Corp. v. Perkins, 317 U.S. 501, 509 (1943).

[96] *Id.* at 150.

[97] *Id.* at 154.

[98] *Id.* at 155.

[99] *Id.* at 156.

[100] *Id.* at 157. In fact, HHS had already described the distinction between the condition requiring treatment and the "handicap" which is illegitimate as a ground for discrimination under section 504. It did so in the supplemental information published with the Final Rule on Jan. 12, 1984:

> [W]here the handicapping condition and the condition to be treated are the same. . .the "handicap" is the physical or mental impairment the infant has or will have (or "is

Next, the Second Circuit reviewed the legislative history of section 504 and concluded that "Congress never contemplated that section 504 would apply to treatment decisions of this nature."[101] It quoted with approval Judge Gesell's *dicta* in his opinion striking down the Interim Final Rule: "[N]o congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking. . . ."[102]

Finally, the court took the position that requiring a hospital to go to court or to child protective services agencies to override parental refusals of consent to their children's lifesaving treatment "would impose a particularly onerous affirmative action burden on the hospital."[103] Although it conceded that the precedent was "not directly on point," the Second Circuit quoted the 1979 Supreme Court decision in *Southeastern Community College v. Davis*[104] distinguishing between the "evenhanded treatment of qualified handicapped persons" required by 504 and "affirmative efforts to overcome the disabilities caused by handicaps" not required by 504.[105] Therefore, the Second Circuit held that section 504 did not authorize the type of investigation that had precipitated this lawsuit.[106]

The government did not ask the Supreme Court to review *University Hospital*. Baby Jane Doe's parents changed their minds, directing that their daughter be given life-preserving surgery;[107] with the risk to her life removed, the government no longer saw a need to pursue the case.

Bowen v. American Hospital Association

Following the Second Circuit's decision in *University Hospital*, the American Hospital Association amended its complaint in an existing suit, and the American Medical Association filed a separate suit, to challenge the four mandatory components of the Final Rule.[108] The plaintiffs in both suits asserted that the Final Rule was beyond the authority of HHS under section 504. The two suits were consolidated.[109]

The district court, regarding the legal issues as having been settled by the holdings in *University Hospital*, concluded that the mandatory provisions of the Final Rule were "invalid, unlawful and must be set aside pursuant to the Administrative Procedure Act, because [these provisions were] promulgated without statutory authority."[110] The district court issued an extremely broad injunction prohibiting HHS from:

> regarded as having") *after* completion of the treatment under consideration. . . .[I]f the surgery would. . .be likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding. . .fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is *because* of the handicap and *in spite of* the infant's being qualified to receive the surgery.

Final Rule (504), *supra* note 25, at 1637 (emphasis in the original).

[101] 729 F.2d at 157. The legislative history of section 504 described at the beginning of this chapter paints a different picture. *See supra* notes 6–12 and accompanying text.

[102] *Id.* at 159, *quoting* Am. Academy of Pediatrics v. Heckler, 561 F. Supp. at 401.

[103] *Id.* at 160.

[104] 442 U.S. 397 (1979).

[105] *University Hospital*, 729 F.2d at 160, *quoting Davis*, 442 U.S. at 410. HHS took the position that hospitals generally do go to court or to child protection agencies to override parental refusals of consent to lifesaving treatment for nondisabled children (when, for example, parents refuse to consent to blood transfusions for their children for religious reasons), so that requiring them to do so on behalf of children with disabilities merely mandates evenhanded treatment, not affirmative action. Final Rule (504), *supra* note 25, at 1,631.

[106] *University Hospital*, 729 F.2d at 161. Circuit Judge Ralph Winter dissented. He wrote:

> [In adopting section 504,] Congress was persuaded that a handicapped condition is analogous to race and that, so far as the administration of federal financial assistance is concerned, discrimination on the basis of a handicap should be on statutory par with discrimination on the basis of race.
>
> . . .A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment.

Id. at 162.

[107] Kerr, *Baby Doe's Success*[:] *Legal, Medical Legacy of Case*, Newsday, Dec. 7, 1987, at 2, col. 2, 23, col. 1.

[108] Additional plaintiffs included the Hospital Association of New York State, the American College of Obstetricians and Gynecologists, the Association of American Medical Colleges, the American Academy of Family Physicians, and individual physicians. Bowen v. Am. Hosp. Ass'n, 476 U.S. 610, 613, n.2 (1986).

[109] *Bowen*, 476 U.S. at 620.

[110] Am. Hosp. Ass'n v. Heckler, 585 F. Supp. 541, 542 (S.D.N.Y.), *aff'd without opinion* 794 F.2d 676 (2d Cir. 1984), *aff'd sub nom.* Am. Hosp. Ass'n v. Bowen, 476 U.S. 610 (1986) (citation omitted).

> any further implementation of the Final [Rule. . .and from] any other actions. . .to regulate treatment involving impaired newborn infants taken under authority of Section 504, including currently pending investigation and other enforcement actions.[111]

The Second Circuit summarily affirmed the district court in an unpublished opinion.[112]

By a vote of five to three, the Supreme Court also affirmed. However, only four Justices joined in the opinion, making it a nonbinding plurality, rather than a majority, opinion.[113] Justice Stevens wrote the plurality opinion, in which Justices Powell, Marshall, and Blackmun joined. Former Chief Justice Burger concurred in the judgment without an opinion and without explaining his refusal to join Stevens' decision. Justices White, O'Connor, and Brennan dissented, and Justice Rehnquist took no part in the decision.

The plurality acknowledged that section 504 protects a child with a disability from discrimination solely by reason of the person's disability: "[H]andicapped infants are entitled to 'meaningful access' to medical services provided by hospitals, and. . .a hospital rule or state policy denying or limiting such access would be subject to challenge under Section 504."[114] However, noting that the suit arose out of a facial challenge to the Final Rule and was not an enforcement action in a particular case, the plurality opinion declined to express a view on whether section 504 "ever applies to individual medical treatment decisions involving handicapped infants," thus refusing to reach the central issue decided by the Second Circuit.[115]

Instead, Justice Stevens focused on what the plurality regarded as a lack of evidence in the administrative record sufficient to support the regulation: "It is an axiom of administrative law that an agency's explanation of the basis for its decision must include 'a "rational connection between the facts found and the choice made."'"[116] Substantial evidence had been assembled by HHS demonstrating widespread denial of treatment to children with disabilities, but Stevens pointed out that in the cases documented, the children's parents had agreed not to give consent for treatment: "A hospital's withholding of treatment when no parental consent has been given cannot violate section 504, for without the consent of the parents or a surrogate decisionmaker the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap.'"[117]

This, perhaps the central point in the plurality opinion, stimulated the U.S. Commission on Civil Rights to invite extensive testimony and undertake substantial research focusing on the interrelationship of parents and physicians in the making of treatment decisions. The evidence thus gathered has been analyzed in chapter 2 of this report. In the view of the Commission, it provides convincing proof that, in the words of Professor James Ellis:

> [The Stevens plurality opinion] misperceives the nature of the process by which parents, in conjunction with their doctors, make decisions about handicapped newborns.
>
> . . . .
>
> . . .All of the literature suggests and all of the accounts by parents, including those who testified before [the Commission], suggest that. . .it's one in which parents look to their physician for information, seek guidance from their physician and, although they ultimately have the formal and ultimate decision, often that's shaped by what they're told. And discrimination can take place in what they're told.[118]

In dissent in *Bowen*, Justices White and Brennan raised this very point:

> [T]he parental consent decision does not occur in a vacuum. In fact, the doctors (directly) and the hospital (indirectly) in most cases participate in the formulation of the final parental decision and in many cases substantially influence that decision. Consequently, discrimination against a handicapped infant may assume guises other than the outright refusal to treat once parental consent has been given. Discrimination may occur when a doctor encourages or fails to discourage a parental decision to refuse consent to treatment for a handicapped child when the doctor would discourage or actually oppose a parental decision to refuse consent to the same treatment for a

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[111] 476 U.S. at 625 n. 11.

[112] *Id.* at 620.

[113] *Cf.* United States v. Pink, 315 U.S. 203 (1942): "[T]he lack of an agreement by a majority of the Court on the principles of law prevents [an opinion] from being an authoritative determination for other cases." *Id.* at 216 (citation omitted).

[114] *Bowen*, 476 U.S. at 624.

[115] *Id.*

[116] *Id.* at 626, *quoting* Motor Vehicle Mfrs. Ass'n v. State Farm Mut., 463 U.S. 29, 43 (1983) and Burlington Truck Lines v. United States, 371 U.S. 156, 168 (1962).

[117] *Bowen*, 476 U.S. at 630. Since section 504 applies only to recipients of Federal financial assistance and parents are not such recipients, section 504 does not reach decisions by parents themselves to withhold consent for treatment solely on the basis of handicap.

[118] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 18 (1986) (vol. II) (testimony of James W. Ellis, School of Law, University of New Mexico).

> nonhandicapped child. Or discrimination may occur when a doctor makes a discriminatory treatment recommendation that the parents simply follow. Alternatively, discrimination may result from a hospital's explicit laissez-faire attitude about this type of discrimination on the part of doctors.[119]

However, the plurality could not find such reasoning or evidence for it in the administrative record: "The Secretary. . .has not even adumbrated a theory of 'discrimination' remotely resembling the one invented by the dissent, and therefore has not made the essential connection between the evidence of physician attitudes and the regulatory choice made here."[120]

Because the plurality believed that the administrative record then before it supplied no basis for this approach to a justification of the HHS investigations and regulatory action, Justice Stevens' plurality opinion did not reach the question of what effect the existence of such an administrative record might have had on the ruling in *Bowen*. It did, however, briefly raise two potential objections to such an approach.

"[T]he dissent's theory," Justice Stevens wrote, "rests on the unstated premise that the statute may prevent the giving of advice to do something which Section 504 does not itself prohibit. It is hardly obvious that the Rehabilitation Act of 1973 forbids physicians from 'aiding and abetting' a parental decision which parents admittedly have a right to make."[121]

But most civil rights laws, when they do not reach purely private discrimination, nevertheless prohibit cooperation with it by the State or by those who may be held accountable for their use of public money. "That the Constitution may compel toleration of private discrimination in some circumstances does not mean that it requires state support for such discrimination."[122] Section 504 exists to ensure that tax funds are not used to participate in or foster discrimination based on handicap. A regulation dating to 1977 includes in the list of discriminatory actions prohibited by section 504 an attempt to "[a]id or perpetuate discrimination against a qualified handicapped person by providing significant assistance to. . .[a] person that discriminates on the basis of handicap in providing any aid, benefit, or service to beneficiaries of the [recipient's] program."[123]

Justice Stevens' second objection was based on the first amendment. "[O]ne might expect an explanation from the Secretary," he wrote, "as to how the hotlines and emergency on-site inspections contemplated by the Final [Rule] square with the constitutional doctrines on regulation, direct or indirect, of speech in general and of decisionmaking by health care professionals in particular."[124]

This objection misconceives the protections the Constitution affords to freedom of speech. A physician is protected by the first amendment in making the general claim that children with disabilities ought to be denied lifesaving medical treatment, just as she or he would be in advocating in general terms the violent overthrow of the government. But a physician is no more protected in using words to bring about denial of treatment to a particular child in violation of section 504 than she or he would be in using words to conspire in a specific and particular attempt to assassinate the President. "[T]he constitutional guarantees of free speech and free press do not permit a State to forbid or proscribe advocacy of. . .law violation *except where such advocacy is directed to inciting or producing imminent lawless action and is likely to incite or produce such action.*"[125] The exception is tailormade for circumstances in which health care personnel urge the parents to opt for denial of lifesaving medical treatment to a particular otherwise qualified child solely on the basis of the child's handicap.[126]

As the plurality recognized, HHS independently sought to justify the Final Rule on the ground that "a hospital's failure to report parents' refusals to consent to treatment violates Section 504, and that past breaches of this kind justify federal oversight."[127] Justice Stevens recognized that "a hospital's selective refusal to report medical neglect of handicapped infants might violate Section 504. . .if the hospital failed to report medical neglect of a handicapped infant when it would report such neglect of a similar nonhandicapped infant."[128] Nevertheless, the plurality considered that "the Secretary has failed to point to any specific evidence that this has occurred,"[129] and therefore concluded the regulation was not adequately supported by the administrative record.[130]

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[119] 476 U.S. at 658–59 (White & Brennan, JJ., dissenting).

[120] *Id.* at 637 n.22 (plurality opinion).

[121] *Id.* at 636–37 n.22.

[122] Norwood v. Harrison, 413 U.S. 455, 463 (1973).

[123] 45 C.F.R. §84.4(b)(v) (1987).

[124] 476 U.S. at 637 n.22.

[125] Brandenburg v. Ohio, 395 U.S. 444, 447 (1969) (emphasis added).

[126] The argument that there may be some constitutional right of physicians that precludes governmental action to protect the rights of children with disabilities to be free of discriminatory denial of medical treatment is laid to rest by Whalen v. Roe, 429 U.S. 589 (1977). There, the Court held that a physician's right to administer medical care is no greater than the patient's right to receive it—that, in effect, any constitutional rights physicians possess specifically in their role as physicians is only a derivative one. *Id.* at 604, n.33.

[127] *Bowen*, 476 U.S. at 637.

The plurality opinion leaves a puzzling gap between the logic of its analysis and the apparent breadth of the plurality's description of the Court's injunction. Nothing in Justice Stevens' analysis suggests that HHS should be prevented from investigating instances in which it *is* alleged that a recipient of Federal financial assistance is failing to report medical neglect solely because the victim has a disability,[131] only that HHS had provided insufficient evidence of the prevalence of discriminatory nonreporting to provide an administrative justification for the Final Rule. Yet, Justice Stevens wrote, "the injunction forbids continuation or initiation of regulatory and investigative activity directed at instances in which parents have refused consent to treatment. . . ."[132] Taken literally, that might appear to forbid investigations of discriminatory nonreporting by a Federal financial assistance recipient, nonreporting that, of course, could only become an issue when parents have at least nominally refused consent.[133]

Because there was no binding majority opinion, and because the plurality opinion is ambiguous, it might be appropriate for the Department of Health and Human Services to act to enforce section 504 in a well-documented instance of discriminatory failure to report as a way of ultimately obtaining clarification or adjustment from the Court.

Enforcement of section 504 is contingent, of course, on receipt of Federal financial assistance by the source of alleged discrimination. In the plurality opinion, Justice Stevens wrote: "We do not address the question whether reporting, either as a hospital practice or as a requirement of state law, constitutes a 'program or activity receiving Federal financial assistance' under Section 504."[134] The Commission concludes that passage of the Civil Rights Restoration Act eliminates this concern, since it defines "program or activity" under section 504 as including "all of the operations of. . .an entire corporation, partnership, or other private organization. . .which is principally engaged in the business of providing. . .health care. . . ."[135] If a hospital engages in reporting cases of medical neglect to the State child protective services agency, that is part of the operations of a corporation that principally provides health care; if any part of the hospital receives medicaid or medicare, discrimination based on handicap in the reporting operation, therefore, violates section 504.

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[128] *Id.* at 637 n.23. Justice Stevens wrote:

> Because respondents have challenged the Secretary's regulations on their face, we have no occasion to address the question whether infants with birth defects are similarly situated with infants in need of blood transfusions (the paradigm case in which hospitals have reported or have sought to override parental decisions. . .) or whether a hospital could legitimately distinguish between the two situations on the basis of the different risks and benefits inhering in certain operations to correct birth defects, on the one hand, and blood transfusions, on the other hand.

Id. at 637-38 n.23. Naturally, if consent for treatment is withheld, not because there is a preference that the child die, but because the risks to the child's life from the treatment appear to outweigh the chance that the treatment would be successful in preserving the child's life, there is no violation of section 504.

[129] *Bowen*, 476 U.S. at 637-38.

[130] The plurality also regarded as unjustified HHS directives to State child protective services agencies that receive Federal financial assistance concerning the manner in which they should process reports of medical neglect of children with disabilities and the priority they should give to them:

> The Final Rule also order[s] state agencies to "immediate[ly]" review reports from hospitals, §84.55(c)(1)(iii), to conduct "on-site investigation[s]," *id.*, and to take legal action "to compel the provision of necessary nourishment and medical treatment," §84.55(c)(1)(iv)—all without regard to the procedures followed by state agencies in handling complaints filed on behalf of nonhandicapped infants. . .
>
> The complaint-handling process the Secretary would impose on unwilling state agencies is totally foreign to the authority to prevent discrimination conferred on him by Section 504. . . .
>
> . . . . .
>
> . . .Even if a state agency was scrupulously impartial as between the protection it offered handicapped and nonhandicapped infants, it could still be denied federal funding for failing to carry out the Secretary's mission with sufficient zeal.

Id. at 639-41.

[131] But see text accompanying note 134, *infra.*

[132] *Bowen* 476 U.S. at 625, n.11.

[133] The dissent took note of this point:

> The plurality apparently would enjoin all enforcement actions by the Secretary in situations in which parents have refused to consent to treatment. . . .Yet it is not clear to me that the plurality's basis for invalidating these regulations would extend to all such situations. I do not see, for example, why the plurality's finding that the Secretary did not adequately support his conclusion that failures to report refusals to treat likely result from discrimination means that such a conclusion will *never* be justified. The Secretary might be able to prove that a particular hospital generally fails to report nontreatment of handicapped babies for a specific treatment where it reports nontreatment of nonhandicapped babies for the same treatment. . . .The fact that the Secretary has not adequately justified generalized action under the regulations should not mean that individualized action in appropriate circumstances is precluded.

Id. at 2132 (White & Brennan, JJ., dissenting).

[134] *Id.* at 2119 n.25.

[135] Pub. L. No. 100-259, §4, 102 Stat. 29 (1988), codified at 29 U.S.C. §793(b)(3)(A)(ii) (Supp. 2, July 1988).

Importance of Section 504 Enforcement

Although there is another basis for Federal enforcement of the right to treatment of children born with disabilities—the Child Abuse Amendments of 1984,[136] which are described in the next chapter—enforcement of section 504 would provide certain advantages not present in the Child Abuse Amendments alone. For one, section 504 reaches medical discrimination against people with disabilities of any age; unlike the Child Abuse Amendments, its coverage is not limited to children. For another, the Child Abuse Amendments apply only to States that choose to accept Federal funding for their child abuse programs.[137] In fiscal year 1988, four States—including California, the Nation's most populous—were not covered by the amendments.[138] Even in the other States, there are a number of ways in which the amendments are inferior to section 504 in protecting against medical discrimination. As James Bopp, Jr., a member of the President's Commission on Mental Retardation and the director of a legal services program specializing in denial of medical treatment to people with disabilities, testified:

> [T]he remedies available in Section 504 are superior. The Child Abuse Amendments of 1984 require, at the pain of loss of Federal funds, State child protective service agencies to act. That is quite in contrast with the application of Section 504, which provides a substantive law standard for the entities that are discriminating against persons with disabilities in the delivery of medical care, which are hospitals and hospital employees and others who are recipients of Federal financial assistance. So the Child Abuse Amendments are quite indirect in their ability to influence the discrimination that is occurring within hospitals.
>
> Second, section 504 provides for private remedies, remedies where a child who is denied treatment can go to Federal court and insist upon treatment if a hospital would deny treatment or, second, may seek damages to compensate him for his injuries.
>
> Third, actions by State child abuse and neglect agencies only occur on a case-by-case basis. Section 504, in contrast, can be the subject of a class action. . . .The Child Abuse Amendments only would involve a case-by-case protection of then-alive infants that are denied treatment, whereas under section 504 you can get injunctive relief to prohibit the hospital from using this form of criteria and protect all future infants.[139]

The Commission heard revealing testimony from pediatric neurologist Dr. Patricia Ellison concerning the comparative effect of the section 504 regulations and those under the Child Abuse Amendments of 1984. When the section 504 rules were issued, she said, discussions about stopping lifesaving treatment in the neonatal intensive care unit "promptly ceased." Because physicians feared getting into trouble, "They treat[ed], and they continue[d] to treat." By contrast, under the Child Abuse Amendments, because physicians have "long worked with people in child abuse[,]. . .we would be surprised if it were an overwhelmingly interfering system. . .and one doesn't expect that they will be doing a lot of newborn investigation by and large."[140]

It creates a strange anomaly for the Federal Government to mandate that State agencies enforce detailed national standards that forbid medical discrimination, while permitting Federal funds to be used for programs that are engaged in the same discrimination. The Federal Government enforces racial and sexual antidiscrimination standards for recipients of its funds; it should do the same to prevent medical discrimination against persons with disabilities.

Conclusion

The Commission's reading of the legislative history and plain meaning of section 504 persuade it that the provision does cover discriminatory denial of medical treatment to people with disabilities. A central problem with the *Bowen* plurality opinion is that it suggests that section 504 puts no constraints on a Federal financial assistance recipient's discriminatory denial of treatment to a person with a disability if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child's medical treatment. (The logic of the plurality opinion applies equally to such authorizations by other surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities.) In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient's involvement, would be prohibited discrimination. A recipient's substantial involvement in a nonrecipient's discriminatory practices should be held to violate section 504.

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[136] Pub. L. No. 98-457, tit. 1, §§121-28, 98 Stat. 1749, 1752-55 (codified at 42 U.S.C.A. §§ 5101-5103 (West Supp. 1988)).

[137] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 35 (1986) (vol. II) (testimony of James W. Ellis, School of Law, University of New Mexico). *Accord, id.* at 159 (testimony of James Bopp, Jr., President, National Legal Center for the Medically Dependent and Disabled).

[138] Telephone interview with Mary McKough, Program Analyst, National Center for Child Abuse and Neglect, Department of Health and Human Services (Dec. 2, 1988). Ohio received funds in prior fiscal years, but was denied FY 1988 funds for reasons unrelated to the Baby Doe requirements. *Id.*

[139] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 162 (1986) (vol. II) (testimony of James Bopp, Jr., President, National Legal Center for the Medically Dependent and Disabled).

[140] *Id.* at 240-41 (testimony of Patricia Ellison, M.D.). Dr. Owens concurred. *Id.* at 241 (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.).

The Commission's hearings and research summarized in chapter 2 supply information related to the issue that the Court considered not to have been satisfactorily addressed in the administrative record at the time *Bowen* was decided. Chapter 2 demonstrates that decisions nominally made by parents to deny treatment to children with disabilities often may, in fact, be generated by health care personnel who act as the agents of health care facilities. In such cases, health care providers who do not provide lifesaving medical treatment to children with disabilities that would be provided were it not for the disabilities should be held to violate section 504 despite parental acquiescence in the treatment denial.

In light of this, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends that the Executive branch give careful consideration to resuming investigation of allegations that children with disabilities are discriminatorily denied medical treatment based on handicap and initiate enforcement of section 504 in cases in which the allegations are found to be justified.[141]

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[141] The Commission does not consider that this course of action would violate the decision of the Supreme Court in *Bowen*. First, the analysis in the plurality opinion depends almost entirely on the nature of the administrative record then before the Court. This report, by supplying information missing from that record, provides a basis for reopening many of the questions the plurality resolved against HHS. Second, this report provides a basis for concluding that the "decisions" by many parents to deny treatment are not truly the product of informed consent; hence, it is questionable that they offer a legally valid or binding consent. Since the injunction bars investigation only of cases "in which parents have refused consent to treatment," *Bowen*, 476 U.S. at 625 n.11, investigations of instances in which it is suspected that parents have not given a legally binding consent to denial of treatment are not enjoined.

Chapter 7

The Child Abuse Amendments of 1984

While HHS was responding to the public furor aroused by the Bloomington Infant Doe case by issuing its Notice to Health Care Providers and, later, the first version of the section 504 Baby Doe regulations,[1] Members of Congress were also reacting.[2] On May 26, 1982, Representative John Erlenborn introduced a bill to prevent denial of treatment to children with disabilities—a bill that, in substantially modified form, eventually became the Child Abuse Amendments of 1984.[3] The bill was designed to create a private right of action against any person using the facilities of a health care facility who sought to "deprive a handicapped infant of nutrition which is necessary to sustain life, or deprive a handicapped infant of medical treatment which is necessary to remedy or ameliorate a life-threatening medical condition, if. . .any such deprivation is carried out for the purpose of causing or allowing the death of such infant; and. . .such nutrition or medical treatment generally is provided to similarly situated infants and handicapped infants."[4]

The bill was not acted upon in 1982, but, on March 3, 1983, a significantly altered version was introduced by Representative Austin Murphy, Chairman of the House Select Education Subcommittee, Representative John Erlenborn, the ranking minority member of the House Education and Labor Committee, and a number of other cosponsors.[5] This bill would have required States receiving funds under the Child Abuse Prevention and Treatment Act[6] to establish "procedures. . .to be followed by child protective service agencies, health care facilities, health and allied medical professionals, such other agencies or individuals as a State may deem appropriate, social service providers, and courts of competent jurisdiction, to insure that nutrition (including fluid maintenance), medically indicated treatment, general care, and appropriate social services are provided to infants at risk with life-threatening congenital impairments."[7]

The House committee reported an amended version of the bill on May 16, 1983. Under this version, as described by the House committee report, the Secretary of Health and Human Services was to conduct a study of the incidence of denial of treatment and then:

> [to] promulgate guidelines to encourage and assist the States in establishing local health care review mechanisms for health and allied professionals and facilities that provide care to those at risk infants. These local review mechanisms would include medical professionals, disability representatives, and persons concerned with the rights

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[1] See chap. 6.

[2] *See, e.g.*, Newborn Baby Starves to Death in Bloomington, Indiana, 128 Cong. Rec. 7143–44 (1982) (statement of Representative Hyde); *A Question of "Equal Justice Under Law,"* 128 Cong. Rec. 12171–72 (1982) (statement of Representative Erlenborn).

[3] Pub. L. No. 98–457, tit. 1, §§121–28, 98 Stat. 1749, 1752–55, codified at 42 U.S.C.A. §§5101–5103 (West Supp. 1988).

[4] H.R. 6492, 97th Cong., 2d Sess., sec. 3, §202 (1982).

[5] H.R. 1904, 98th Cong., 1st Sess. (1983).

[6] This act established a program of Federal financial assistance to State agencies for the identification, prevention, and treatment of child abuse and neglect. It also created the National Center on Child Abuse and Neglect to facilitate the gathering and dissemination of information on child abuse, as well as to keep records on the incidence of child abuse. The underlying act was amended and extended several times. Pub. L. No. 93–247, 88 Stat. 4 (1974), codified at 42 U.S.C.A. §§5101–5106 (West 1983 & Supp. 1988). *See id.* §5101 note (West 1983 & Supp. 1988) for citations to other amending legislation.

[7] H.R. 1904, 98th Cong., 1st Sess. sec. 103(a)(3) (1983).

> of the infants. The review mechanism would provide special consideration of the uniqueness of each case while the child was being cared for, and would not prevent either the parents or health care professionals or others on the review mechanism from utilizing other procedures to appeal any findings and conclusions. In a case where the parents, attending physicians and review mechanism concur to not treat an infant, an automatic referral of the case shall be made to a child protection agency to assure that the decision was made on medical considerations and not solely based on other considerations such as the future quality of life or future disabling conditions.[8]

In an effort to satisfy objections from medical organizations, the principal sponsors and committee staff prepared amendments to the legislation after it was reported to delete the HHS incidence study, to make the "local review mechanisms" optional for each hospital, and to allow the required procedures to be incorporated into existing State child protective services procedures.[9] Nevertheless, medical organizations lobbied against the bill,[10] and the Waxman-Chandler amendment was proposed on the House floor "to eliminate the current Baby Doe provisions from the bill and to provide instead for local review committees to advise families and physicians on a case-by-case basis."[11] This amendment was defeated by a vote of 231 to 182, with 20 not voting.[12]

On September 28, 1983, the Senate Committee on Labor and Human Resources reported its version of the legislation. The committee report stated that the problems required "greater scrutiny and remedial action."[13] Declaring that there was a "sufficient body of evidence" indicating that infants with disabilities were being denied treatment,[14] it stated, "this practice is not isolated to one or two instances."[15] The Senate committee bill would have established an advisory committee to the Secretary of Health and Human Services to "conduct a comprehensive study of decision making procedures in health care facilities that involve the medical management of seriously ill handicapped infants."[16] The advisory committee was to complete its study in 6 months, after which the Secretary could issue regulations "concerning the establishment of local decision-making procedures with regard to seriously ill handicapped infants which procedures will at a minimum guarantee that each health care facility will provide such infants proper feeding and appropriate medications for pain and sedation," regulations that the hospitals would have to follow or lose Federal financial assistance.[17]

Disability rights groups considered the Senate committee version unacceptable because it failed to provide what they considered adequate guarantees for treatment and because of its reliance on internal hospital self-policing. After these views were made widely known, six Senators whose views spanned the ideological spectrum (Orrin Hatch, Christopher Dodd, Jeremiah Denton, Alan Cranston, Don Nickles, and Nancy Kassebaum) and their staffs encouraged representatives of the interest groups involved to negotiate a compromise amendment.[18] Thomas Nickels, legislative director and counsel to the American Nurses Association, told the Commission: "[I]t seemed to us [that] we perceived very clearly that there was a mood in the Congress that there should be some process by which reporting could occur. . . .We got involved because we wanted to have a say in how that process worked. . . ."[19]

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[8] H.R. Rep. No. 159, 98th Cong., 1st Sess. 2-3 (1983).

[9] Murphy, Committee Explanation of the Child Abuse Reauthorization, H.R. 1904 (undated) (letter to colleagues circulated shortly before House floor debate) (available in files of U.S. Commission on Civil Rights). *See also* 130 Cong. Rec. 1433 (1984).

[10] *See* Letter to Members of Congress from American Academy of Pediatrics, American Association of Medical Colleges, American Psychiatric Association, National Association of Children's Hospitals and Related Institutions, American Academy of Family Physicians, American Medical Association, American Hospital Association, Federation of American Hospitals, and American College of Obstetricians and Gynecologists (Nov. 4, 1983); letter to Members of Congress from American College of Obstetricians and Gynecologists (Nov. 7, 1983); Letter to Members of Congress from American Hospital Association (Jan. 31, 1984) (available in files of U.S. Commission on Civil Rights).

[11] Letter to Colleagues from Reps. Henry Waxman, John Dingell, Rod Chandler, James Quillen, and J. Roy Rowland (Nov. 14, 1983) (available in files of U.S. Commission on Civil Rights).

[12] 130 Cong. Rec. 1442-43 (1984).

[13] S. Rep. No. 246, 98th Cong., 1st Sess. 11, *reprinted in* 1984 U.S. Code Cong. & Admin. News 2918, 2928.

[14] *Id.*

[15] *Id.* at 16, 1984 U.S. Code Cong. & Admin. News at 2933.

[16] *Id.* at 16, 1984 U.S. Code Cong. & Admin. News at 2933.

[17] *Id.* at 17, 1984 U.S. Code Cong. & Admin. News at 2934.

[18] Interview with Thomas Nerney, disability rights group representative present at the negotiations (Sept. 19, 1988). Staff from the office of Sen. Edward Kennedy were also involved in the negotiations. *Id.* Gary J. Caruso, former Legislative Director of the House Select Subcommittee on Education of the Committee on Education and Labor, told the Commission: "[A] number of Democrats and Republicans on both sides. . .felt that this was a civil rights matter that should be addressed. And when all the groups finally saw that the Democrats and Republicans. . .were going to act on something, they got involved." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 234 (1985) (vol. I).

A precedent existed for negotiations among medical and disability rights groups in connection with the Baby Doe issue. In 1983, under the auspices of the Office for Special Education and Rehabilitative Services in the Department of Education,[20] disability rights and medical groups negotiated a set of "Principles of Treatment of Disabled Infants." The document was signed on November 29, 1983, after 7 months of discussions. With respect to medical care, it provided:

> When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration[s] such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.
>
> It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.
>
> In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.[21]

These principles were to be referred to frequently in the negotiations over the Child Abuse Amendments. Those negotiations were lengthy and intense.[22] They eventually produced an agreement that was announced in the *Congressional Record* on June 29, 1984, in the form of proposed statutory language and a "Joint Explanatory Statement" by the principal sponsors of the compromise amendment.[23] This statement was to serve the legislative history function of a committee report.

The Senate passed the compromise amendment on July 26, 1984, by voice vote and the amended bill by a vote of 89–0.[24] On September 19, 1984, the conference committee reported an agreed bill that essentially incorporated the Senate-passed compromise version. Furthermore, the conference committee report included most of the Principal Sponsors' Statement.[25] The conference committee version was adopted by the House on September 26 and by the Senate on September 28.[26] The President signed it into law on October 9, 1984.[27]

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[19] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 57 (vol. I) (1985). Dr. James Strain, past president of the American Academy of Pediatrics, testified: "I think we became aware, as the discussion went on, that there was a growing need to have something in place. We weren't terribly enthusiastic about this to begin with, frankly. But when it became apparent that there was a good deal of concern. . .[w]e felt it was better to get in and make our suggestions to try to develop a law that would be workable." *Id.* at 56.

[20] Interview with Thomas Nerney, former expert consultant, Office for Special Education and Rehabilitation Services, U.S. Department of Education (Sept. 19, 1988).

[21] *Joint Policy Statement: Principles of Treatment of Disabled Infants,* 73 Pediatrics 559 (1984) [hereinafter *Principles of Treatment*]. The signatories were the Association for Retarded Citizens, the National Down's Syndrome Congress, the American Coalition of Citizens with Disabilities, Inc., the Association for Persons with Severe Handicaps, the American Association on Mental Deficiency (now the American Association on Mental Retardation), the American Association of University Affiliated Programs, Persons with Developmental Disabilities, the Spina Bifida Association of America, the National Association of Children's Hospitals and Related Institutions, Inc., and the American Academy of Pediatrics.

[22] Among groups represented at one time or another in the negotiations were the American Medical Association (which ultimately actively opposed the compromise), the American Hospital Association, the American Academy of Pediatrics, the American Nurses Association, the National Association of Children's Hospitals and Related Institutions, the American College of Obstetricians and Gynecologists, the Nurse's Association of the American College of Obstetricians and Gynecologists, the American College of Physicians, the California Association of Children's Hospitals, the Catholic Health Association, the National Right to Life Committee, the American Life Lobby (which ultimately actively opposed the compromise), the Christian Action Council, the Association for Retarded Citizens of the United States, the American Association on Mental Deficiency, the Spina Bifida Association of America, the Down's Syndrome Congress, People First of Nebraska, the Association for Persons with Severe Handicaps, the Disability Rights Center, and Operation Real Rights.

[23] 130 Cong. Rec. S8951 (daily ed. June 29, 1984) [hereinafter Principal Sponsors' Statement]. *See also* Association for Retarded Citizens of the United States, Compromise Reached on "Baby Doe" Legislation, Press Release (July 2, 1984) (available in files of U.S. Commission on Civil Rights).

[24] 130 Cong. Rec. S9307, S9328 (daily ed. July 26, 1984).

[25] H.R. Conf. Rep. No. 1038, 98th Cong., 2nd Sess. 40 (1984), *reprinted in* 1984 U.S. Code Cong. & Admin. News 2947, 2969 [hereinafter Principal Sponsors' Statement].

[26] 1984 U.S. Code Cong. & Admin. News 2918.

[27] 98 Stat. 1749 (1984).

Under the law, the Department of Health and Human Services was obligated to promulgate regulations to implement the act and to publish model guidelines for hospital-based infant care review committees.[28] These committees are voluntary under the 1984 amendments, as are the guidelines suggested for them.[29] A proposed implementing regulation was published by HHS on December 10, 1984.[30] In excess of 116,000 comments, most of them favorable, were received on the proposed regulation.[31]

On April 15, 1985, the HHS promulgated the Final Rule. In addition to the regulation itself, HHS published an appendix containing "Interpretative Guidelines." The Interpretative Guidelines were in large part derived from part of the proposed regulation. In response to critical comments from medical organizations, HHS decided to remove the clarifying definitions from the final regulation itself. However, because HHS continued "to believe that guidance relating to interpretations of key terms. . .will aid in effective implementation of the statute (a belief shared by many commenters)," it incorporated its understanding of them into the appendix.[32] HHS wrote:

> In publishing these interpretative guidelines, the Department is not seeking to establish them as binding rules of law, nor to prejudge the exercise of reasonable medical judgment in responding to specific circumstances. Rather, this guidance is intended to assist in interpreting the statutory definition so that it may be effectively and rationally applied in specific cases so as to fully effectuate the statutory purpose of protecting disabled infants.[33]

Thus, the Interpretative Guidelines give "all parties the benefits of very relevant interpretations of the statute by the agency charged with its implementation."[34]

The relevant provisions of the Child Abuse Amendments of 1984 and their implementing regulation became effective on October 9, 1985.[35] As of December 1988, four States—California, Indiana, Ohio, and Pennsylvania—did not receive funds under the Child Abuse Prevention and Treatment Act, and the law did not apply to them.[36] The remaining 46 States, the District of Columbia, and Puerto Rico receive grants under the act, and the provisions of the amendments apply in these jurisdictions.[37]

A sizable number of children with disabilities, those in the States that do not receive funds under the act, are not protected by the Child Abuse Amendments. Moreover, the funding the Federal Government provides through the underlying act is meager in comparison to that under other Federal programs: in fiscal year 1988, each compliant eligible jurisdiction received an annual base of $35,000 and an additional amount depending on the number of residents under the age of 18. Payments ranged from a high of $739,006 (Texas) to a low of $35,980 (Commonwealth of the Northern Mariana Islands).[38] As a result, the financial incentive for States to comply is not very great.[39]

The Standard of Care

As noted by the six principal Senate sponsors, each word in the standard of care enacted by the amendments "was chosen with utmost care."[40] Their nuances require careful analysis.[41] Under the law, for a State to be eligible for Federal funds, it must have in place procedures to respond to reports of medical neglect; the definition given to medical neglect in the context of denial of treatment to children with disabilities is the meticulously negotiated federally required standard of care.

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[28] Child Abuse Amendments of 1984, 42 U.S.C.A. §5103 note (West Supp. 1988).

[29] See chap. 11 for a detailed consideration of the HHS model guidelines for infant care review committees issued in accordance with the amendments.

[30] Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. 48160 (1984) (to be codified at 45 C.F.R. pt. 1340) (proposed Dec. 10, 1984) [hereinafter Proposed Rule (CAA)].

[31] Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14879 (1985) (codified at 45 C.F.R. pt. 1340) [hereinafter Final Rule (CAA)].

[32] *Id.* at 14880.

[33] *Id.*

[34] *Id.* at 14882.

[35] *Id.* at 14878.

[36] Telephone interviews with Mary McKeough, Program Analyst, National Center for Child Abuse and Neglect, Office of Human Development Services, Department of Health and Human Services (Dec. 2 & 5, 1988).

[37] *Id.*

[38] *Id.* The former trust territory is funded under a different formula. *Id.*

[39] In the words of Commissioner Blandina Cardenas Ramirez: "When I was in HHS, which was HEW at the time, the Child Abuse Act was one of the ones I was responsible for. . . . [I]t was very difficult to get the States to comply because you had no stick and very little carrot." Transcript, Meeting of the United States Commission on Civil Rights 142 (Nov. 18, 1988).

[40] Final Rule (CAA), *supra* note 31, at 14879.

[41] *See generally* Mumaw, *The Child Abuse Amendments of 1984: The Infant Doe Amendment*, 18 Akron L. Rev. 515 (1985); Bopp & Balch, *The Child Abuse Amendments of 1984 and their Implementing Regulations: A Summary*, 1 Issues in L. & Med. 91 (1985).

Perhaps the best short statement of the medical standard of care established by the Child Abuse Amendments of 1984 is found in the Supplemental Information HHS published with the Proposed Rule:

> [F]irst, all such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication. Second, all such disabled infants must be given medically indicated treatment. Third, there are three exceptions to the requirement that all disabled infants must receive treatment, or, stated in other terms, three circumstances in which treatment is not considered "medically indicated."[42]

The required standard of care may be divided for the purpose of convenient analysis into nine elements: (1) a disabled (2) infant (3) with a life-threatening condition (4) must always be given nutrition, hydration, and medication (5) and must normally be given the treatment most likely to correct or ameliorate the condition (maximal treatment) (6) based upon the reasonable medical judgment of the treating physician, (7) but the maximal treatment rule is not applicable in three situations: when the child is "chronically and irreversibly comatose," (8) when maximal treatment would be futile in saving the child's life for long, and (9) when "provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."[43]

Disabled

"Disabled" is not expressly defined in the statute, its implementing regulations, or the HHS Interpretative Guidelines. However, some light is cast upon its meaning by the legislative history. The original formulation of what became "disabled infants with life-threatening conditions" in the statute was "infants at risk with life-threatening congenital impairments" in the House-passed bill.[44] Concern was expressed that this language would be interpreted to cover only those disabled infants whose life-threatening condition arose directly from a congenital impairment.[45] The enacted language clarifies that the 1984 amendments protect all infants with a disability, including those who develop a disability after birth, from withholding of medically indicated treatment for any life-threatening condition, regardless of whether the condition is related to the disability.

Model Procedures developed under a Federal grant by the American Bar Association's Commission on the Mentally Disabled and the National Legal Resource Center for Child Advocacy and Protection suggest the following meaning for the term "disabled":

> "Disabled infant" means an infant with a physical or mental impairment which substantially limits or holds the reasonable prospect of in the future substantially limiting one or more major life activities. "Major life activities" include functions such as, but not limited to, breathing, seeing, hearing, walking, caring for one's self, performing manual tasks, learning and working.[46]

The Model Procedures explain that this definition is based on the definitions of "[h]andicapped person," "[p]hysical or mental impairment," and "[m]ajor life activities" in the implementing regulations for section 504 of the Rehabilitation Act of 1973,[47] except that "the phrase 'or holds the reasonable prospect of in the future substantially limiting [a major life activity]' is added. This reflects the fact that infants and young children, in the normal course of development, do not yet possess the capability of performing many of the enumerated 'major life activities.'"[48]

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[42] Proposed Rule (CAA), *supra* note 30, at 48163.

[43] The statute prohibits "withholding of medically indicated treatment from disabled infants with life-threatening conditions," 42 U.S.C.A. §5103(b)(2)(K) (West Supp. 1988), and defines the key term as follows:

> [T]he term "withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id. §5102(3).

[44] The House Committee report interpreted this original language to mean that those to be protected by the law were infants who are "born with a medically-identifiable handicapping condition and a life-threatening condition, the latter of which requires medical intervention in order to increase the infant's changes [sic] of survival." H.R. Rep. No. 159, 98th Cong., 1st Sess. 2 (1983).

[45] Bopp & Balch, *supra* note 41, at 107.

[46] Nicholson, Horowitz & Parry, *Model Procedures for Child Protective Service Agencies Responding to Reports of Withholding Medically Indicated Treatment From Disabled Infants With Life-Threatening Conditions*, 10 Mental & Physical Disability L. Rep. 220, 228 (1986) [hereinafter *Model Procedures*].

[47] *Id.* These definitions are found in 45 C.F.R. §84.3 (j) (1987). They are not part of the "Baby Doe" regulations enjoined by the U.S. Supreme Court in Bowen v. Am. Hosp. Ass'n, 476 U.S. 610 (1986), but are part of the preexisting 1977 regulation implement-

In addition to one who actually *has* such an impairment, the Rehabilitation Act includes one who "is [erroneously] regarded as having such an impairment."[49] That category was incorporated in the amended Rehabilitation Act to ensure that those subjected to discrimination because they are erroneously believed to have a disability receive the same protection under the law as those who actually have a disability. If this group were not included among those protected by the Child Abuse Amendments, then when lifesaving treatment is denied a child based on a mistaken prognosis of degree of disability, the very fact that the prognosis is mistaken might prevent the denial of treatment from being overturned.

Infant

Those protected by the standard of care are disabled infants with life-threatening conditions. The term "infants" includes, but is not limited to, children under 1 year of age. The first birthday is not an automatic cutoff from protection under the statute. The Principal Sponsors' Statement stated that although the law was intended primarily to protect infants under 12 months, it was not to be construed to justify discontinuance of otherwise mandated treatment at that age.[50] Accordingly, the Final Rule provides that the law "shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age."[51]

Again tracking the Principal Sponsors' Statement, the Final Rule also provides that the standard of care "should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability."[52] The Supplemental Information HHS published with the Final Rule explained this definition by noting that, as a condition of receiving child abuse and neglect grants, States must have procedures that protect children of all ages from medical neglect.

> [A]s a general rule, issues of medical treatment for infants over one year of age are to be considered under the less precisely defined, but clearly applicable, standards of "medical neglect." Issues of medical treatment for disabled infants under one year of age with life-threatening conditions must be considered under the more precisely defined standards of the definition of "withholding of medically indicated treatment."
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> [But f]or certain infants over one year of age, the Conference Committee believed the more precisely defined standards of the definition of "withholding of medically-indicated treatment" might be more appropriate to use in considering the question of medical treatment than the more general standards of "medical neglect." . . .The apparent Congressional intent is to recognize that these three categories of infants, although over one year of age, share important characteristics with those infants under one year of age who are the principal focus of the statutory provision.[53]

It is noteworthy that the third category, those over 1 year of age who have "a long-term disability," is extremely broad. Thus, it is arguable that under the law the more precise standards should be consulted concerning medical treatment decisions for practi-

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ing section 504 in general. They are based on the statutory language of the Rehabilitation Act of 1973 itself. 29 U.S.C.A. §706 (West Supp. 1988).

[48] *Model Procedures, supra* note 46, at 228.

[49] 29 U.S.C.A. §706(8)(B)(iii) (West Supp. 1988).

[50] Principal Sponsors' Statement, *supra* note 25, at 41, 1984 U.S. Code Cong. & Admin. News at 2970.

[51] 45 C.F.R. §1340.15(b)(3)(i) (1987).

[52] *Id.*

[53] Final Rule (CAA), *supra* note 31, at 14882.

cally all children with disabilities, of whatever age.[54]

Life-Threatening Conditions

Under the Interpretative Guidelines, a life-threatening condition includes a condition that, in the physician's "reasonable medical judgment, significantly increases the risk of the onset of complications that may threaten the life of the infant."[55] The intent of this clarification was to deal with circumstances in which a condition does not in and of itself threaten life but, unless corrected, poses the danger of a life-threatening condition developing. The Supplementary Information published with the Proposed Rule gave the example of spina bifida, in which the open lesion on the back does not, of itself, threaten life, but a failure to close the lesion surgically leaves an open pathway for a life-threatening infection.[56]

Nutrition, Hydration, and Medication

"Appropriate" nutrition, hydration, and medication must always be supplied, even when one of the three exceptions to required maximal treatment applies.

In cases concerning adults, a considerable number of courts have rejected any distinction between the provision of nourishment and the provision of maximal treatment: when it would be inappropriate to cut off the latter, they have ruled, it is equally appropriate to terminate the former.[57] In clear contrast to this approach, Congress plainly placed itself on the side of the dissenting judge in the 1986 Massachusetts case *Brophy v. New England Sinai Hospital* who wrote, "The process of feeding is simply *not* medical treatment. . . .Food and water are basic human needs."[58] Surgeon General C. Everett Koop had testified before the Senate Committee on Labor and Human Resources:

> [T]he bottom line. . .is that you must nourish the patient. Whether an infant in a hospital is denied food and care, or whether an infant at home is denied food and care, the result is the same; it is child abuse.[59]

On the Senate floor, one of the principal sponsors of the 1984 amendments affirmed that "the words 'appropriate nutrition [and] hydration'. . .are not meant to sanction outright denial of all nutrition and hydration but are intended only to affirmatively require appropriate nutrition and hydration in all cases[.] In other words, nothing in this amendment allows an infant to be denied nutrition and hydration. . . ."[60] In addition, the HHS Interpretative Guidelines affirm:

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[54] Presumably the term "infant" itself puts some limits on such a construction. Indeed, HHS suggested as much:

> [N]o revision is necessary to clarify that "infant" does not include older children and adults. The potential appropriateness of applying the more precisely stated standards of the definition of "withholding of medically indicated treatment" to certain infants over one year of age is still stated, as it was in the proposed rule and in the Conference Report, in terms of *infants* over one year of age. Older children and adults are not "infants over one year of age."

Id. at 14882. However, "infant" can encompass a broad gamut of ages, especially in its use as a legal term. Black's Law Dictionary defines "infancy" as "Minority; the state of a person who is under the age of legal majority,—at common law, twenty-one years; now, generally 18 years." Black's Law Dictionary 699 (5th ed. 1979). Webster's gives a range of meanings for the term, including not only "a child in the first year of life" and "a child several years of age" but also "a person who is not of full age: minor" and "*common law:* a person under the age of 21." Webster's Third New International Dictionary 1157 (P. Grove ed. 1986) (emphasis in original). The Oxford English Dictionary includes the definition, "A person under (legal) age; a minor. In common law, one who has not completed his or her twenty-first year. . . ." Oxford English Dictionary 1426 (1971). When the applicability of legal standards is at stake, ambiguity of the sort that now exists in the definition of those covered by the Child Abuse Amendments is regrettable.

[55] 45 C.F.R. pt. 1340 App. Interpretative Guideline 2 (1987); *see* Bopp & Balch, *supra* note 41, at 107.

[56] Proposed Rule (CAA), *supra* note 30, at 48163. *But cf.* note 96, *infra.*

[57] *See* Corbett v. D'Alessandro, 487 So.2d 368 (Fla. App. 2 Dist.), *review denied,* 492 So.2d 1331 (1986); *In re* Drabick, 245 Cal. Rptr. 840 (Cal. App. 6 Dist.), *cert. denied,* 57 U.S.L.W. 3347 (1988); Severns v. Wilmington Medical Center, 421 A.2d 1334 (Del. Supr. 1980); *In re* Gardner, 534 A.2d 947 (Me. 1987); Brophy v. New England Sinai Hosp., 398 Mass. 417, 497 N.E.2d 626 (1986); *In re* Hier, 18 Mass. App. 200, 464 N.E.2d 959, *rev. denied,* 392 Mass. 1102, 465 N.E.2d 261 (1984); *In re* Jobes, 108 N.J. 394, 529 A.2d 434 (1987); *In re* Conroy, 98 N.J. 321, 486 A.2d 1209 (1985); Delio v. Westchester County Medical Center, 129 App. Div. 2d 1, 516 N.Y.S.2d 677 (2d Dept. 1987); *In re* Grant, 109 Wash.2d 545, 747 P.2d 445 (1987), *corrected,* 757 P.2d 532 (Wa. 1988); *see also* cases dealing with persons who expressed their wishes while competent: Bouvia v. County of Los Angeles, 195 Cal. App. 3d 1075, 241 Cal. Rptr. 239 (2d Dist 1987); Bouvia v. Superior Court, 225 Cal. Rptr. 297 (Cal. App. 2d Dist. 1986); *In re* Peter, 108 N.J. 365, 529 A.2d 419 (1987); *cf.* Leach v. Akron General Medical Center, 68 Ohio Misc. 1, 426 N.E.2d 809 (1980) (the court did not make a decision on whether nutrition and hydration could be removed); later proceeding, Estate of Leach v. Shapiro, 13 Ohio App. 3d 393, 469 N.E.2d 1047 (Summit Co. 1984); *contra In re* Steinhaus, No. J–86–92, Amended Findings of Fact and Order at 3 (Redwood County Ct. Fam. Div. Minn. Oct. 13, 1986) (court ruled that nutrition, hydration, or medication could not be withdrawn from an infant who was chronically and irreversibly comatose, although resuscitation could be, in light of the 1984 Child Abuse Amendments and conforming Minnesota legislation).

[58] 398 Mass. 417, 497 N.E.2d 626, 640 (1986) (Nolan, J., dissenting).

[59] *Quoted in* S. Rep. No. 246, 98th Cong., 1st Sess. 10, *reprinted in* 1984 U.S. Code Cong. & Admin. News 2918, 2927.

> [I]t should be clearly recognized that the statute is completely unequivocal in requiring that all infants receive "appropriate nutrition, hydration, and medication," regardless of their condition or prognosis.[61]

It is difficult to contend, therefore, that under the Child Abuse Amendments it can ever be appropriate to withhold nutrition or hydration from a child with a disability who is capable of assimilating it. Instead, the legislation requires that basic sustenance be provided in the form "appropriate" to the patient's condition. For example, if a patient is incapable of receiving food and liquids orally, the patient might most appropriately receive nutrition and hydration through such measures as intravenous fluids, nasogastric or gastric tube feedings, or hyperalimentation.[62]

The same absolute requirement that applies to nourishment also applies to "medication." It seems clear that the congressional intent was to require that pain-relieving and other palliative medicine be given even to those children from whom maximal medical treatment is withheld. Before the final legislation was drafted, Dr. George Little testified:

> Obligations to comfort and respect a dying person remain, and infants whose lives are destined to be brief are owed whatever enhancement and relief from suffering that can be provided, including medication for pain and sedation, as appropriate.[63]

The Principles of Treatment adopted by medical and disability groups articulated a similar baseline standard of care:

> It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected.[64]

In the case of *In re Steinhaus*, a Minnesota court held that antibiotics to deal with infection are included in the required medication.[65]

Treatment Most Likely to Be Effective in Ameliorating or Correcting All Life-Threatening Conditions

The centerpiece of the Child Abuse Amendments' standard of care is found in this phrase. It is the care that must be provided to all children covered by the law unless one of the three exceptions to be discussed below applies.

The history of the wording is instructive. Soon after Senate negotiations began on the standard of care, staff of the Senate Committee on Labor and Human Resources suggested a definition for the "medically indicated treatment" to be required that sought to incorporate the nondiscrimination approach of section 504. It required "treatment which would normally be provided to infants without regard to the presence of disabling conditions and includes treatment specifically designed to ameliorate a disabling condition."[66] Later drafts also incorporated the nondiscrimination approach with various modifications.

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[60] 130 Cong. Rec. S9322 (daily ed. July 26, 1984) (Colloquy between Senators Helms and Hatch). The Principal Sponsors' Statement said: "[T]he six principal sponsors of this compromise measure. . .[intend] that this statement. . .be the definitive legislative history in the Senate on it. Any remarks of individual Senators, including the principal sponsors, on this legislation express only their personal views and do not, therefore, constitute authoritative interpretation or explanation of the measure." 130 Cong. Rec. S9319 (daily ed. July 26, 1984). However, the interpretation of Senator Hatch was never challenged by any other sponsor and appears to parallel the unequivocal language of the statute itself. It is useful primarily as an aid in understanding the importance attached to this aspect of the legislation at the time of passage.

[61] 45 C.F.R. pt. 1340 App. Interpretative Guideline 10 (1987).

[62] Major disability organizations strongly oppose starvation or dehydration of people with disabilities. For example, the Association for Retarded Citizens of the United States, noting that "debate is currently taking place concerning the appropriateness of withdrawing food and fluids from some persons labeled 'comatose' or 'in a permanent vegetative state'" and recognizing that persons so labeled "may appear to share many characteristics with some persons labeled 'profoundly mentally retarded'" resolved that the group "opposes the cessation of nutrition and/or hydration for the purpose of hastening or causing the death of persons with mental retardation." *ARC Resolution on Cessation of Nutrition and/or Hydration*, 3 Issues in L. & Med. 313 (1987) (resolution adopted Oct. 25, 1986). Similarly, the Association for Persons with Severe Handicaps adopted a resolution stating that the group "strongly opposes any cessation of nutrition and hydration for people who are incapacitated. . . ." *TASH Resolution on Nutrition and Hydration*, 3 Issues in L. & Med. 315 (1987) (resolution adopted Nov. 15, 1986).

[63] *Quoted in* S. Rep. No. 246, 98th Cong., 1st Sess. 10, *reprinted in* 1984 U.S. Code Cong. & Admin. News 2918, 2927.

[64] *Principles of Treatment, supra* note 21, at 559.

[65] *In re* Steinhaus, No. J-86-92, slip op. at 10 (Minn. Redwood County Ct., Juv. Div. Sept. 11, 1986), *reprinted in Order in the Steinhaus Case*, 2 Issues in L. & Med. 241, 246–47 (1986).

[66] Gerry & Nimz, *The Federal Role in Protecting Babies Doe*, 2 Issues in L. & Med. 339, 345 (1987), *quoting* Senate Labor and Human Resources Staff Discussion Draft of Proposed Amendments to S. 1003 (May 18, 1984). An earlier draft from Sen. Edward Kennedy's staff would have required "that all such newborns be provided treatment provided to other similarly situated children without congenital impairments that is necessary to correct or ameliorate a life-threatening condition, relief from suffering including feeding, and medication for pain and sedation

When face-to-face negotiations among advocacy groups began, however, medical groups instead proposed language requiring "medical or surgical treatment, including treatment specifically designed to ameliorate a disabling condition, when such failure is clearly contrary to the best interests of the infant."[67] The "best interests" language was rejected because it would have allowed consideration of projected quality of life,[68] but the approach of requiring specifically defined treatment, instead of simply employing the nondiscrimination or equal protection approach of the earlier drafts, was retained. Further negotiations resulted in the language used in the statute as adopted: "'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions."[69]

This definition creates a high standard of care—indeed, a higher standard of care than would equal protection language alone. Children covered by the law must be provided the treatment "most likely to be effective," not just the level of treatment that would be provided to their nondisabled counterparts. This places a responsibility on physicians to become knowledgeable about and employ the best available treatment rather than simply to avoid discriminating on the basis of disability.

The Interpretative Guidelines issued by the Department of Health and Human Services contain a number of clarifications of the scope of the standard of care. The Department emphasized:

> [T]he definition's focus on the potential effectiveness of treatment in ameliorating or correcting life-threatening conditions makes clear that it does not sanction decisions based on subjective opinions about the future "quality of life" of a. . .disabled person.[70]

The Interpretative Guidelines stated that treatment means more than a "particular medical treatment or surgical procedure"; it refers to a "complete potential treatment plan," including "multiple medical treatments and/or surgical procedures over a period of time. . .designed to ameliorate or correct a life-threatening condition or conditions."[71] Treatment also includes diagnostic procedures to evaluate the need for medical intervention, including, as appropriate, "further evaluation by, or consultation with, a physician or physicians whose expertise is appropriate to the conditions(s) involved or further evaluation at a facility with specialized capabilities regarding the condition(s) involved. . . ."[72] Finally, if palliative treatment makes a condition more tolerable, even though the condition will not be cured, that treatment is required.[73]

Reasonable Medical Judgment

Under the 1984 amendments, the determination of what "will be most likely to be effective in ameliorating or correcting all [life-threatening] conditions" is to be made "in the treating physician's or physicians' reasonable medical judgment."[74] By requiring that the physician determine what the most effective treatment will be, the provision avoids the problem encountered in some cases in which the physician determined not what would be the treatment most likely to preserve life, but whether the treatment would produce a child with an acceptable quality of life.[75]

Deference to "reasonable medical judgment" was not intended to authorize physician discretion to

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as appropriate." Gerry & Nimz, *supra*, at 345, *quoting* Second Draft of Proposed Amendments to S. 1003 from Sen. Edward Kennedy's Staff (late April 1984).

[67] Gerry & Nimz, *supra* note 66, at 347, *quoting* Memorandum to Staff/Organizations re S. 1003 from Susanne Martinez (June 19, 1984).

[68] Gerry & Nimz, *supra* note 66, at 347.

[69] *Id.* at 348. The language now appears at 42 U.S.C.A. §5102(3) (West Supp. 1988).

[70] 45 C.F.R. pt. 1340 App. Interpretative Guideline 1 (1987).

[71] *Id.*, Interpretative Guideline 4.

[72] *Id.*, Interpretative Guideline 3.

[73] *Id.*, Interpretative Guideline 7. This interpretation is discussed more fully below in the context of the futility exception.

[74] 42 U.S.C.A. §5102(3) (West Supp. 1988).

[75] In Maine Medical Center v. Houle, Civ. No. 74-145 (Me. Super. Ct., Feb. 14, 1974), *reprinted in Trial Court Decision in Houle Case*, 2 Issues in L. & Med. 237 (1986), for example, the pediatrician for a child with disabilities who in addition had a tracheoesophageal fistula testified:

> I feel he [the infant] has already endured much insult to his brain and that considering the total child. I do not believe he will be able to function as a reasonable, normal child in late life. I honestly believe that with the insults of the last twenty-four hours, that he will be severely both motor and mentally retarded.

Quoted in Brown & Truitt, *Euthanasia and the Right to Die*, 3 Ohio N.U.L. Rev. 615, 633 (1976). The judge rejected the physician's quality of life analysis, holding that "the doctor's qualitative evaluation of the value of the life to be preserved is not legally within the scope of his expertise." *Houle*, slip op. at 4, 2 Issues in L. & Med. at 238-39.

avoid the explicit standards set forth in the legislation, but only to recognize the role of technical medical judgment in determining whether the conditions to which the legal standards refer exist in particular cases.[76] This distinction has been described by Loretta Kopelman, Ph.D., Thomas Irons, M.D., and Arthur Kopelman, M.D.:

> [The law] only indicates that physicians are permitted to use reasonable medical judgment to determine whether the guidelines' conditions have been met. . . .[T]he guidelines must allow such appraisals by physicians if they are to be applied. In contrast, the traditional understanding of reasonable medical judgment includes not only such technical or scientific assessments but moral judgments about what is in the patients' best interests. The Baby Doe guidelines do not allow doctors, nurses, review committees, or state investigators to use their own views about which exceptions constitute reasonable medical judgment. Permitted exceptions to the provision of maximal treatment are spelled out in the rules; other behavior is defined as medical neglect. Hence, no deference is shown to reasonable medical judgment as traditionally understood—a judgment that includes moral as well as technical considerations of the proportional benefits of alternative treatments in alleviating suffering and in prolonging life.[77]

While rejecting the incorporation of nonmedical factors into "reasonable medical judgment," the law creates a high standard for that judgment on the technical level. Testifying before the Senate Committee on Labor and Human Services, Surgeon General Koop said:

> The physician must know a great deal about the infant's disease process or disabling condition. As science and medicine continue to evolve, this is an ever-growing responsibility and requires that physicians must have great knowledge about and experience with the [condition] in question. . . .[78]

Accordingly, the Principal Sponsors' Statement provided: "The reference to 'reasonable medical judgment' of the treating physician or physicians means a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved."[79] HHS adopted this definition verbatim in the Final Rule.[80] For the physician to be knowledgeable about the case and treatment possibilities, information which surpasses that with which the ordinary physician is familiar may be required. Reasonable judgments in life and death situations often will decree consultation and further evaluation.[81] Nevertheless, as the American Bar Association's Model Procedures pointed out: "This standard of care is used widely in other treatment contexts, and only its application to the issue of withholding of medically indicated treatment from disabled infants with life-threatening conditions is new."[82]

Exceptions to Providing Treatment

The Child Abuse Amendments create three exceptions to the requirement to provide the treatment most likely to correct or ameliorate a child's life-threatening conditions (maximal treatment)—although "appropriate nutrition, hydration, and medication" must always be provided.

The Comatose Exception

The first exception applies when a child is "chronically and irreversibly comatose."[83] The medical groups originally proposed an exception to cover those who are "permanently and completely unconscious."[84] "Unconscious" is defined as "insensible" or "not conscious."[85] The disability rights groups rejected this proposal as too broad and proposed the more restrictive language now in the law.[86] "Coma" has a precise meaning:

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[76] In the words of the Model Procedures developed by the American Bar Association: "[T]he decision to withhold medical treatment or care from a disabled infant with life-threatening conditions is to be made only in terms of the statutory definition. This definition does not include nonmedical factors in the 'reasonable medical judgment' used to determine 'withholding of medically indicated treatment.'" *Model Procedures, supra* note 46, at 227. The Model Procedures point out that principles of treatment jointly adopted by medical and disability groups state: "considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decision concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards." *Id., quoting Principles of Treatment, supra* note 21, at 559.

[77] Kopelman, Irons, & Kopelman, *"Baby Doe" Regulations* (letter to the editor), 319 New Eng. J. Med. 726 (1988).

[78] *Quoted in* S. Rep. No. 246, 98th Cong., 1st Sess. 10, *reprinted in* 1984 U.S. Code Cong. & Admin. News 2918, 2927.

[79] Principal Sponsors' Statement, *supra* note 25, at 41, 1984 U.S. Code Cong. & Admin. News at 2970.

[80] 45 C.F.R. §1340.15(b)(3)(ii) (1987).

[81] *See supra* note 72 and accompanying text.

[82] *Model Procedures, supra* note 46, at 227. The Model Procedures paraphrase W. Prosser, Handbook of the Law of Torts §32, at 161 (1982): "[P]hysicians who undertake work requiring special skill are required to possess a minimum standard of special knowledge and ability." *Model Procedures, supra* note 46, at 246 n.28.

[83] 42 U.S.C.A. §5102(3)(A) (West Supp. 1988).

[84] Gerry & Nimz, *supra* note 66, at 349, *quoting* Proposed Amendment to S.1003 by Medical Groups (June 25, 1984).

[85] Stedman's Medical Dictionary 1512 (24th ed. 1982).

> *Coma* was defined operationally as a sleeplike, unarousable, unresponsive state in which the patient shows no awareness of self or environment. Such patients (1) do not open their eyes either spontaneously or in response to any verbal stimulus, (2) utter no comprehensible words, and (3) neither obey commands nor move their extremities appropriately to localize or to resist noxious stimuli.[87]

In the 1986 Minnesota case *In re Steinhaus*, the court ruled that although the statute makes an exception for those who are "chronically and irreversibly comatose," it makes no exception for those in a "persistent vegetative state."[88] In an article on persistent vegetative state, Dr. Philip Hansotia wrote that, in contrast to those in a coma:

> Patients in the PVS [persistent vegetative state],. . . .are awake without being aware. They open their eyes and look about randomly but do not follow objects or respond to verbal command. The eyes open and blink spontaneously and to menace but are unattentive. Patients may sleep at times. Chewing and bruxism [grinding of teeth] are common, and a grasp reflex is often present.[89]

The Futility Exception

The second exception applies when:

> [T]he provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant. . . .[90]

When life is inevitably ebbing away, and dying cannot be halted but only prolonged, the interest in preserving life can no longer be satisfied. This exception was designed to ensure that in such circumstances there would be no requirement that life-prolonging treatment be employed to eke life out for a brief period longer. The HHS Interpretative Guidelines state that the exception does not "apply where many years of life will result from the provision of treatment, or where the prognosis is not for death in the near future, but rather the more distant future."[91]

In its proposed rule, HHS used the word "imminent" to define the period within which death must be expected in order to make the exception applicable.[92] However, the Senate sponsors of the compromise legislation wrote a joint letter objecting to the term:

> In the negotiations leading to the final language, there was much discussion about whether or not to include the word "imminent" in the statutory definition. It became apparent that "imminent" would create undue confusion both because it was ambiguous and because the expected time of death cannot be predicted with precision. A decision was made, therefore, not to include "imminent," and we urge that it be dropped in the regulations as well.[93]

Accordingly, in the Interpretative Guidelines accompanying the Final Rule, HHS retracted the term "imminent" and indicated that the precise determination of what is a "near" versus a "more distant" future was left to reasonable medical judgment.[94]

The second category of the second exception specifically addresses circumstances in which death will inevitably occur shortly even though some life-threatening conditions could be cured. As two legal commentators have noted:

> In HHS' view, this [exception] was intended to apply to situations in which an infant suffers from several life-threatening conditions, some of which can be treated effectively, but at least one of which cannot. If and only if the untreatable condition will produce death in the near

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[86] Gerry & Nimz, *supra* note 66, at 349.

[87] Hansotia, *Persistent Vegetative State*, 42 Arch. Neurol. 1048, 1048 (1985) (emphasis in original).

[88] Transcript at 73, *In re* Steinhaus, No. J-86-92 (Minn. Redwood County Ct., Fam. Div., Oct. 6, 1986); *In re* Steinhaus, No. J-86-92, slip op. at 11-12 (Minn. Redwood County Ct., Juv. Div. Sept. 11, 1986), *reprinted in Order in the Steinhaus Case*, 2 Issues in L. & Med. 241, 247-48 (1986). The court later ruled that the child was in fact chronically and irreversibly comatose. *In re* Steinhaus, No. J-86-92, Amended Findings of Fact and Order 3 (Minn. Redwood County Ct., Fam. Div. Oct. 13, 1986).
Lance Steinhaus received serious injuries when just over a month old and became unconscious. After a decision was made not to give him antibiotics and to place a "Do Not Resuscitate" order on his medical chart, the county welfare department petitioned the court to prevent the withholding of antibiotics. After the court ruled that he was chronically and irreversibly comatose and that treatment other than nutrition, hydration, and medication could legally be withheld, the "Do Not Resuscitate" order was restored. *Agreement Will Allow Comatose Baby to Die*, The Sun, Oct. 25, 1986, at A10. He subsequently died. *Baby Who Was Subject of Right-to-Live Case Dies*, Minneapolis Star and Tribune, Feb. 11, 1987, at 1A, col. 1.

[89] Hansotia, *supra* note 87, at 1048. *See also* Levy, *The Comatose Patient*, in I The Clinical Neurosciences 955, 956 (R. Rosenberg ed. 1983):

> The patient in the *vegetative state* appears awake but shows no evidence of content, either confused or appropriate. He often has sleep-wake cycles but cannot demonstrate an awareness either of himself or his environment.

Id. (emphasis in original) (footnote omitted).

[90] 42 U.S.C.A. §5102(3)(B) (West Supp. 1988).

[91] 45 C.F.R. pt. 1340 App. Interpretative Guideline 5 (1987).

[92] Proposed Rule (CAA), *supra* note 30, at 48164, 48167.

[93] *Quoted in* Final Rule (CAA), *supra* note 31, at 14879.

[94] 45 C.F.R. pt. 1340 App. Interpretative Guideline 5 (1987).

(as opposed to the far) future, then treatment need not be provided for the other life-threatening conditions which theoretically could be treated. In other words, if the child is going to die shortly anyway from ailment A, it makes no sense (and is not required) to treat ailments B, C, or D. If, on the other hand, the child is terminally ill from ailment A, but will not die from it for some time, this exception provides no excuse for failing to treat the immediate threats to life from ailments B, C, or D.[95]

HHS also interpreted the law to require that palliative care, including treatment that goes beyond medication,[96] must be provided even when lifesaving treatment would not be effective:

> If. . .palliative treatment will ameliorate the infant's *overall* condition, taking all individual conditions into account, even though it would not ameliorate or correct *each* condition, then this palliative treatment is medically indicated.[97]

The third category in the second exception applies if treatment would "otherwise be futile in terms of the survival of the infant." This category is simply a "cover all bases" logical extension of the other two categories, each of which describes circumstances in which treatment would be futile. The language, however, carefully ties futility to the "survival" of the infant, emphasizing that only the inevitability of death despite treatment, and not the persistence of disability despite treatment, renders the treatment legally futile.[98]

The Virtually Futile and Inhumane Exception

The third exception reads:

> [T]he provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.[99]

The exception is phrased in the conjunctive: to remove the maximal treatment mandate, both of two requirements must be met.

The first of the requirements is that the treatment be "virtually futile." The distinction between "futile" as used in the second exception and "virtually futile" as used in the third exception lies in the degree of probability or uncertainty in determining the futility of the treatment. Under the Interpretative Guidelines, the term "virtually futile" is understood to mean that treatment is "highly unlikely to prevent death in the near future."[100]

The second requirement of the third exception is that the treatment itself be inhumane. The Interpretative Guidelines state that this is true only in the presence of "significant medical contraindications and/or significant pain and suffering for the infant that clearly outweigh the very slight potential benefit of the treatment for an infant highly unlikely to survive."[101]

The Interpretative Guidelines note that although the initial two exceptions concerned themselves with the expected results of treatment, the third exception focused on the process of possible treatment:

> It recognizes that in the exercise of reasonable medical judgment, there are situations where, although there is some slight chance that the treatment will be beneficial to the patient (the potential treatment is considered *virtually* futile, rather than futile), the potential benefit is so outweighed by negative factors relating to the process of the treatment itself that, under the circumstances, it would be inhumane to subject the patient to the treatment.[102]

Enforcement of the Child Abuse Amendments

While the 1984 amendments were in the process of negotiation under the auspices of Senate staff, Senator Kennedy's office suggested an approach to enforcement that would have "required states, as a condition of continued receipt of federal child abuse funds, to create an ombudsman program for the purpose of protecting and advocating for the interests of newborn infants with life-threatening congenital impairments and infants or children with special needs."[103] This was rejected by the medical groups on the ground that it would lead to undue intrusion. Instead, the American Academy of Pediatrics made a counterproposal giving enforcement authority to State child protective services agencies, the framework that was eventually adopted.[104] Under the statute as enacted, within 1 year after the act became law, such agencies desiring to receive Federal funds would have to:

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[95] Bopp & Balch, *supra* note 41, at 112–13. *See* 45 C.F.R. pt. 1340 App. Interpretative Guideline 6 (1987).

[96] At the time it published the Proposed Rule, HHS gave the example of a child with an uncorrectable and life-threatening heart problem who also had an imperforate anus; in such a situation, the absence of effective treatment for the heart problem would not relieve physicians of the responsibility of providing a colostomy to relieve "the severe pain associated with the intestinal obstruction caused by the imperforate anus." Proposed Rule (CAA), *supra* note 30, at 48164. However, when HHS issued the Final Rule, it noted that commenters had "stated that, depending on medical complications, exact prognosis, relationships to other conditions, and other factors, the treatment suggested. . .might not necessarily be the treatment that reasonable medical judgment would decide would be most likely to be effective. In response to these comments, specific diagnostic examples have not been included in this discussion. . . ." 45 C.F.R. pt. 1340 App. Interpretative Guideline 7 (1987).

[97] 45 C.F.R. pt. 1340 App. Interpretative Guideline 7 (1987) (emphasis in original).

[98] *See* Gerry and Nimz, *supra* note 66, at 349.

[99] 42 U.S.C.A. 5102(3)(C) (West Supp. 1988).

[100] 45 C.F.R. pt. 1340 App. Interpretative Guideline 8 (1987).

[101] 45 C.F.R. pt. 1340 App. Interpretative Guideline 9 (1987).

[102] *Id.* (emphasis in original).

> have in place for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.[105]

The Principal Sponsors' Statement of the Senate sponsors adopted by the conference committee noted that preexisting law required recipient State agencies "to provide certain mechanisms for the reporting of abuse or neglect cases. The same reporting mechanisms and standards set forth in the Act and existing regulations would be applicable to the reporting of cases of medical neglect. . . ."[106]

Those preexisting regulations establish a State duty to create classes of individuals legally required to report both known and suspected cases of child abuse and neglect, a State duty to permit all other persons to submit such reports,[107] and a State duty to investigate promptly to substantiate the accuracy of all such reports.[108]

The HHS Final Rule implementing the Child Abuse Amendments is largely built on these requirements. To ensure that health care facilities take seriously their obligation to designate individuals with the specific responsibility to report known or suspected withholding of medically indicated treatment and to serve as a point of contact and coordination during investigations, it mandates that State agencies contact each health care facility annually to identify the names, titles, and telephone numbers of the designated individuals.[109] It requires that States demonstrate, through statute, regulation, or the opinion of the State attorney general, that their State laws give adequate authority to enable them to prevent violations of the federally defined standard of care.[110]

Perhaps the most important feature of the Final Rule pertaining to enforcement was its emphasis on providing the mechanisms necessary to ensure an independent medical evaluation of circumstances that give rise to a report of suspected medical neglect. As the American Bar Association's Model Procedures point out: "The judgment of physician(s) who specialize in the medical problems and disabling conditions of newborn infants is necessary to assess whether reasonable medical judgment was employed in a decision to withhold medical treatment or care from a disabled infant."[111] A social worker or other child protective services specialist is rarely equipped to make an accurate judgment about whether legally required treatment is being withheld. Short of outright admissions by medical staff, detection of such withholding normally requires a specialist's knowledge of the appropriate level of care for the life-threatening condition, so as to judge whether the treatment being accorded by the health care facility falls short of it. Furthermore, a judgment about what care is appropriate necessarily depends on an accurate diagnosis of the child's condition. Without the assistance of a consultant qualified to make an independent evaluation of that condition, a child protective services worker would in most cases be reduced to relying solely upon the unconfirmed representations of the very physicians whose conduct is the subject of investigation.[112]

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[103] Gerry & Nimz, *supra* note 66, at 344.

[104] *Id.*

[105] 42 U.S.C.A. §5103(b)(2)(K) (West Supp. 1988).

[106] H.R. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 41, *reprinted in* 1984 U.S. Code Cong. & Admin. News 2947, 2970. It made special mention of the requirement that a guardian *ad litem* be appointed for children in the course of all judicial proceedings relating to abuse or neglect. *Id.*

[107] 45 C.F.R. §1340.14(c) (1987).

[108] *Id.* §1340.14(d).

[109] 45 C.F.R. §1340.15(c)(3) (1987).

[110] *Id.* §1340.15(d)(2)(ii) (1987).

[111] *Model Procedures, supra* note 46, at 229.

[112] The analogy in a more "traditional" child abuse case, one in which someone reports that a neighboring child has been severely beaten by her parents, would be a child protective services

It was recognized, therefore, that the key to effective enforcement would be resort to physicians who were at the same time specialists in the field of treatment alleged to have been denied and persons committed to the standards of treatment embodied in the Federal law. HHS sought to provide them the key tools—access to medical records and the ability to conduct an independent medical examination—necessary to enable them to obtain the information essential to make an independent evaluation. Under this approach, there is no need to find a "smoking gun" in the form of proof that treatment has been intentionally denied in order to cause the child's death. It need only be determined, by the consulting expert or experts, that in order to meet the federally defined standard of care, the child needs treatment she or he is not getting.

Accordingly, the Final Rule required that State agencies specify procedures they will employ to obtain access to medical records when necessary for an appropriate investigation of a report of medical neglect, and a court order for an independent medical examination when necessary for an appropriate resolution of such a report.[113]

Conclusion

The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care which States that receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

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worker restricted to asking the parents to describe the child's wounds, without being able to look at the child.

[113] 45 C.F.R. §1340.15(c)(4) (1987). The regulation permitted States to show that they may obtain an independent medical examination in some manner other than with a court order.

Chapter 8

Constitutional Issues

Since the record developed by the Commission demonstrates that persons with disabilities have been denied necessary medical care on the basis of their disabilities,[1] and that neither Federal, State, nor local protective agencies make it a practice to intervene on their behalf,[2] two constitutional questions arise:

First: whether constitutional rights are at stake in disputes over the denial of medical treatment for newborns and other persons with disabilities; and

Second: if so, whether there exist under State and Federal law adequate substantive and procedural safeguards (including a forum) to protect those rights.

Such an inquiry can be obscured by the technical nature of the medical decisionmaking process, the deference the law gives to parental choices alleged to be in the best interests of their children, and the power of the States over matters of family law. Nonetheless, it is important to note that the factual setting of denial of treatment cases is critical to an analysis of their constitutional aspects. Based on the record developed during the Commission's inquiry, at least four basic types of denial of treatment cases can be identified:[3]

1. Cases where the denial of treatment reflects the medical judgment of the attending physicians that the treatment would not be useful to the patient, and that the parents or guardians have given a fully informed consent to the denial of treatment;
2. cases where medical professionals present inadequate or prejudiced information concerning the future quality of life of individuals with the particular disability in question, and the refusal by the parent or guardian to consent to otherwise useful treatment is based on such information;
3. cases where medical and other qualified professionals make a full and fair presentation of the child's present medical needs, the limitations associated with the disability, and the rehabilitation and support services resources available, but the parents refuse consent based on either their own view of the future quality of life of individu-

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[1] See chaps. 1, 9.

[2] See chaps. 10–12. *See also* United States v. Univ. Hosp., 729 F.2d 144 (2d Cir. 1984); Am. Academy of Pediatrics v. Heckler, 561 F.Supp. 395 (D.D.C. 1983); *In re* Infant Doe, No. GU8204–00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.* State of Indiana on Relation of Infant Doe by Guardian, No. 482 S139 (Ind. S.Ct, May 27, 1982), No. 482 S.140 (Ind. S.Ct. Apr. 26, 1983), *cert. denied,* 464 U.S. 961 (1983).

[3] That the factual record is significant to a complete understanding of both the statutory and constitutional policy issues which can arise in denial of treatment cases is illustrated by the U.S. Supreme Court's ruling in Bowen v. Am. Hosp. Ass'n, 476 U.S. 610 (1986). Justice Stevens' opinion for the plurality rested its holding that section 504 of the Rehabilitation Act of 1973 did not apply to denial of treatment cases, where parental consent was refused, where there was a lack of a clear factual record that discrimination on the basis of handicap influenced the parental choice to refuse consent. 476 U.S. at 636 & n.22 (Stevens, J., plurality opinion). *See also,* 476 U.S. at 653–54 & n.7, 656–63 (White, J., dissenting). Given the breadth of the injunction that limits the power of the Secretary of Heath and Human Services to intervene under section 504 on behalf of infants with disabilities, it is arguable that *Bowen* itself is a legal development that may have the effect of leaving unregulated acts which do, in fact, "constitut[e] discrimination or a denial of equal protection of the laws under the Constitution, because of race, color, religion, sex, age, handicap, or national origin or in the administration of justice." 42 U.S.C.A. §1975c(2) (1988). *See* Am. Hosp. Ass'n v. Heckler, 585 F.Supp. 541 (S.D.N.Y., 1984), *aff'd in reliance on* United States v. Univ. Hosp., 729 F.2d 144 (2d. Cir, 1984), 794 F.2d 676 (2d. Cir, 1984). For a full discussion of the *Bowen* case see chap. 6.

als with the particular disability in question or their view of the burden that caring for such a child will place on them or their family; and

4. cases where agencies charged with the protection of children or persons with disabilities have reason to believe that a disability, rather than the need for and usefulness of treatment, was the determinative factor in the decision to deny treatment, and the agency declines to intervene, even though it would do so if the child in question did not have a disability.

Part one of this chapter, therefore, examines the nature and extent of the equal protection and procedural due process constitutional rights at stake in the types of denial of treatment cases raised above. Part two examines the interests and rights of parents as potential substantive limitations on the recognition and protection of such rights, and part three discusses the ability and willingness of courts to protect the rights of newborns denied treatment on the basis of disability. The chapter concludes with a discussion of whether or not there is a need for Federal legislative, administrative, or judicial intervention on behalf of newborn children who are denied treatment on the basis of disability.

The Constitutional Rights of Newborn Children with Disabilities

The constitutional right of newborn children to due process and equal protection of the law is not open to question. Section 1 of the 14th amendment provides in relevant part that:

> All persons born or naturalized in the United States and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law, nor deny to any person within its jurisdiction the equal protection of the laws.[4]

As persons who are also citizens, persons with disabilities, including newborn children,[5] are entitled to the same legal protection of their lives, physical integrity, and procedural due process rights as infants, children, and adults without disabilities.[6]

Equal Protection of the Laws

The legal standards governing discrimination on the basis of handicap or disability are undergoing rapid development as developments in vocational rehabilitation, biotechnology, and medicine influence changes in public attitudes toward those with disabilities.[7] Federal law requires, among other things, that any federally funded program or activity must refrain from discriminating against an "otherwise qualified" individual "solely on the basis of his handicap"[8] and that children with disabilities must be offered equal educational opportunities.[9] Many

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[4] U.S. CONST. amend. XIV, §1. Although this language applies only to the States, the Supreme Court has held that "[t]he federal sovereign, like the States, must govern impartially. The concept of equal justice under law is served by the Fifth Amendment's guarantee of due process, as well as by the Equal Protection Clause of the Fourteenth Amendment." Hampton v. Mow Sun Wong, 426 U.S. 88, 100 (1976). *Accord*, United States Dep't of Agriculture v. Moreno, 413 U.S. 528, 533, n. 5 (1973); Bolling v. Sharpe, 347 U.S. 497, 499 (1954).

[5] *In re* Gault, 387 U.S. 1, 13 (1967) ("[W]hatever may be their precise impact, neither the Fourteenth Amendment nor the Bill of Rights is for adults alone."). *Accord* Thompson v. Oklahoma, 108 S.Ct. 2687 (1988) (death penalty for minors); Goss v. Lopez, 419 U.S. 565 (1975) (procedural due process). The liberty interests of children are also protected, though, in some cases, to a lesser degree than for adults. *See, e.g.*, Hazelwood School Dist. v. Kuhlmeier, 108 S.Ct. 562 (1988); Tinker v. Des Moines School Dist., 393 U.S. 503 (1969); West Virginia Bd. of Educ. v. Barnette, 319 U.S. 624 (1943).

[6] City of Cleburne v. Cleburne Living Center, 473 U.S. 432 (1985) [hereinafter Cleburne Living Center].

[7] *See, e.g.*, Cleburne Living Center, 473 U.S. 432 (1985) (constitutional standard for discrimination against the persons with disabilities in cases involving exclusionary zoning); Consolidated Rail Corp. v. Darrone, 465 U.S. 624 (1984) (coverage of funded programs); Alexander v. Choate, 469 U.S. 287 (1985) (application of "disparate impact" theory as a matter of law or regulation); Smith v. Robinson, 468 U.S. 992 (1984) (relationship of the Education of the Handicapped Act, 20 U.S.C.A. §§1400–1485, (1982) [hereinafter cited as E.H.A.] to section 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. §794 (1982) and the 14th amendment); Bd. of Educ. v. Rowley, 458 U.S. 176 (1982) (extent of rights under E.H.A.); Southeastern Community College v. Davis, 442 U.S. 397 (1979) (limits on reach of section 504). *See also*, Americans with Disabilities Act of 1988, S. 2345, 100th Cong., 2d Sess.

[8] Section 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. §794 (1988) provides in relevant part:

> No otherwise qualified individual with handicaps. . .shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . .

See Consolidated Rail Corp. v. Darrone, 465 U.S. 624 (1984) (Federal funds need not be given with the "primary objective" of promoting employment to subject the recipient to the requirements of section 504). The definition of the term "handicapped individual" is found in 29 U.S.C.A. §706(8)(B) (1988): "the term 'individual with handicaps' means. . .any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

State and local laws provide similar protection.[10] The appropriate place to begin[11] an analysis of the appropriate equal protection standard for "disability" cases is Congress' prohibition against discrimination against those with disabilities in federally funded programs, including its expression of particular concern about medical care discrimination against infants with disabilities.[12]

In a series of cases elaborating on various Federal laws governing the rights of persons with disabilities,[13] the United States Supreme Court has held that the intent of these laws is twofold:[14] to protect those with disabilities from the discriminatory acts of others[15] and to eliminate what might be called "benign neglect" based on "thoughtlessness and indifference."[16] The Court has also held that discrimination on the basis of disability is a violation of the equal protection clause of the 14th amendment when the government is unable to demonstrate that its rationale for the challenged discriminatory activity is grounded in an unprejudiced evaluation of the differences caused by the disability itself.[17]

Cleburne v. Cleburne Living Center

In *City of Cleburne v. Cleburne Living Center,*[18] a unanimous[19] Supreme Court ruled that the equal protection clause forbids exclusionary zoning that would make it impossible for people with mental retardation to live in a neighborhood group home environment.[20] The Court began its discussion of the constitutional standards that govern legislation having an adverse impact on the mentally retarded with a review of the general standards that are applicable to cases raising equal protection claims, and held that mental retardation is not a "quasi-suspect classification calling for a more exacting standard of judicial review than is normally accorded economic and social legislation."[21] Instead, the Court chose a minimum rationality standard, and highlighted the obvious relationship between the social and constitutional concerns that motivated its choice:

> First. . .those who are mentally retarded have a reduced ability to cope with and function in the everyday world. . . .[T]hey range from those whose disability is not immediately evident to those who must be constantly

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[10] *See, e.g.,* Fla. Stat. Ann. §760.10 (West Supp. 1985); N. Dak. Cent. Code §§14–02.4–03 to 4–06, 14–02.4–08 (1981); Ohio Rev. Code §4112.02 (Page 1984); Tenn. Code Ann. §8–50-103, 104 (1979). Unlike the Federal Government, the States are not constrained by a Federal constitutional requirement that nondiscrimination provisions relating to private sector discrimination on the basis of disability must be tied to a funding source or some matter of Federal concern such as interstate commerce. As a result, they may, and do, prohibit private sector discrimination directly.

[11] This is not to say that constitutional and legislative standards are the same, but merely to point out that, whatever the constitutional standard of protection, Congress retains the ability to mandate a minimum level of additional protection which is not otherwise inconsistent with the Constitution. U.S. CONST. amend. XIV, §5. Katzenbach v. Morgan, 384 U.S. 641, 651-52 n.10 (1966).

[12] Child Abuse Amendments of 1984, 42 U.S.C.A. §§5101-5103 (Supp. 1988). For a full discussion of the law, see chap. 7.

[13] See cases cited *supra* note 7.

[14] That the congressional concern was for both the social welfare and the civil rights of persons with disabilities is critically important to an understanding of the Supreme Court's approach to disability cases, and to the approach taken by this Commission in this report and others. See U.S. Commission on Civil Rights, Accommodating the Spectrum of Individual Abilities (1983). There is an inherent relationship between civil rights law and social welfare policy, yet they address separate problems. Persons in need of material or economic assistance often need the legal protection afforded by the civil rights laws. Proof of material need, however, is not necessary to state a claim under the civil rights laws.

[15] *See* Alexander v. Choate, 469 U.S. 287 (1985) (holding that section 504 would clearly cover cases of intentional discrimination against the persons with disabilities, but refusing to hold either that the regulations promulgated under the statute are limited to such cases or that the statute necessarily comprehends the use of "disparate impact" analysis); Consolidated Rail Corp. v. Darrone, 465 U.S. 624 (1984) (coverage of funded programs); Smith v. Robinson, 468 U.S. 992 (1984).

[16] Alexander v. Choate, 469 U.S. 287, 295 & nn. 12-16. (1985). The sources cited in the Court's footnotes make it clear that a bright line was drawn between "thoughtlessness and indifference" which, though neglecting the needs of the persons with disabilities, might be considered "benign" in that they are not intentional or "invidious":

> To be sure, well-catalogued instances of invidious discrimination against the handicapped do exist. See, e.g., United States Commission on Civil Rights, Accommodating the Spectrum of Individual Abilities, Ch. 2 (1983); Wegner, The Antidiscrimination Model Reconsidered: Ensuring Equal Opportunity Without Respect to Handicap Under Section 504 of the Rehabilitation Act of 1973, 69 Cornell L. Rev. 401, 403 n.2 (1984).

469 U.S. at 295, n. 12. Intentional neglect of the needs of persons with disabilities—such as denying food and water (nutrition and hydration) or necessary medical care because the disability is alleged to cause a diminished quality of life—are not "benign."

[17] Cleburne Living Center, 473 U.S. 432 (1985).

[18] 473 U.S. 432 (1985).

[19] Justice Stevens and Chief Justice Burger joined the opinion of the Court, but also filed a concurring opinion advocating a new single tier standard for equal protection analysis. Justices Brennan and Marshall filed an opinion concurring in part and dissenting in part, which argues that the proper standard for disability cases is heightened scrutiny, and that the ordinance should have been declared invalid on its face.

[20] See chap. 4.

[21] Cleburne Living Center, 473 U.S. at 442. For a general discussion of these standards, see *supra* note 7.

> cared for. They are thus different, immutably so, in relevant respects, and the States' interest in dealing with and providing for them is plainly a legitimate one. How this large and diversified group is to be treated under the law is a difficult and often a technical matter, very much a task for legislators guided by qualified professionals and not by the perhaps ill-informed opinions of the judiciary. Heightened scrutiny inevitably involves substantive judgments about legislative decisions, and we doubt that the predicate for such judicial oversight is present where the classification deals with mental retardation. . . .[22]

> Because mental retardation is a characteristic that the government may legitimately take into account in a wide range of decisions, and because both state and federal governments have recently committed themselves to assisting the retarded, we will not presume that any given legislative action, even one that disadvantages retarded individuals, is rooted in considerations that the Constitution will not tolerate.[23]

Although the practical effect of the Court's refusal to deal with equal protection cases involving persons with disabilities at a heightened level of scrutiny is arguably to make it more difficult to challenge State or Federal policies that are alleged to be discriminatory, the majority opinion by Justice White makes it clear that "refusal to recognize the retarded as a quasi-suspect class does not leave them entirely unprotected from invidious discrimination."[24] Even though the Court refused to "presume that any given legislative action, [including] one that disadvantages retarded individuals, is rooted in considerations that the Constitution will not tolerate,"[25] the standard actually applied in *Cleburne* is quite similar to that applied in gender cases: it explicitly requires lower courts to focus on the real reasons behind the challenged unequal treatment and to analyze whether the discriminatory policy is actually related to a legitimate government purpose.

The Supreme Court undertook such an analysis in *Cleburne* and found that the zoning ordinance[26] was invalid under the equal protection clause. It found that the reason for the discriminatory treatment was "the negative attitude of the majority of the property owners located within 200 feet of the. . .facility, as well as the fears of elderly residents of the neighborhood."[27] In short: "an irrational prejudice against the mentally retarded."[28]

Denial of Treatment to Newborn Children with Disabilities

The record of the Commission's inquiry leaves no doubt that newborn children have been denied food, water, and medical treatment solely because they are perceived to be disabled. It is undisputed that the purpose of the denial of treatment was to end the lives of these children because of social, economic, or eugenic factors unrelated to the child's medical need or ability to benefit from the proposed treatment. In some cases, the discriminatory denial of treatment was based on ignorance and false stereotypes about the "quality of life" of persons with disabilities, and in others, about the nature of the particular disability the child would have if he or she were permitted to survive. The testimony of Dr. Walter Owens, the physician who treated the original Baby Doe in Bloomington, Indiana,[29] illustrates the point.

> COMMISSIONER DESTRO. . . .How was the issue of recommending [a] course of treatment posed to the parents?

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[22] Cleburne Living Center, 473 U.S. at 442–43 (footnotes omitted).

[23] *Id.* at 446 (footnotes omitted).

[24] *Id.* at 446. Justice White's opinion for the Court was joined by Chief Justice Burger and Justices Powell, O'Connor, Rehnquist, and Stevens.
The lower court opinions in Cleburne Living Center are instructive as to the operation of the standards of review in practice. The district court was criticized by the Fifth Circuit for using a "minimum rationality" test to uphold the ordinance, both on its face and as applied. The Court of Appeals for the Fifth Circuit held that the proper equal protection test was "heightened scrutiny," and ruled that the ordinance was invalid, both on its face and as applied. 726 F.2d 191 (1984).

[25] Cleburne Living Center, 473 U.S. at 446.

[26] The area in question was zoned "R-3" (apartment house district) and the ordinance permitted the following uses:

1. Any use permitted in District R-2.
2. Apartment houses, or mulitple dwellings.
3. Boarding and lodging houses.
4. Fraternity or sorority houses and dormitories.
5. Apartment hotels.
6. Hospitals, sanitariums, nursing homes or homes for convalescents or aged, other than for the insane or feeble-minded or alcoholics or drug addicts.
7. Private clubs or fraternal orders, except those whose chief activity is carried on as a business.
8. Philanthropic or eleemosynary institutions, other than penal institutions.
9. Accessory uses customarily incident to any of the above uses.

Cleburne Living Center, 473 U.S. at 436 n.3.

[27] *Id.* at 448.

[28] *Id.* at 450.

[29] *In re* Infant Doe, No. GU8204–00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.* State of Indiana on Relation of Infant Doe by Guardian, No. 482 S139 (Ind. S.Ct. May 27, 1982), No. 482 S.140 (Ind. S.Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

> **Dr. Owens.** I think that's a little distortion. They were not recommended courses of treatment but simply alternatives. As I indicated earlier, the pediatrician and Dr. Schafer and the family physician, Dr. Wenzler, were simply saying to them, "This child must go to Riley Hospital to be operated on tonight." I'm not sure they even mentioned the Down's syndrome or they certainly downplayed it and were giving the impression to the family that surgery would make the child okay. Those were their words: "The baby will be okay."
>
> My words to the family were simply, as I said before, that "I think you must realize that if the child has the surgery, and if the surgery is successful, that this child will still be a Down's syndrome child with all that that implies," and as I indicated earlier, the parents were pretty well-acquainted and had a good knowledge of what this implied. I said to them, "There is the alternative of doing nothing, in which case the child will survive a few days and will die." These were not recommendations in that sense at all. These were alternatives presented to the family of what could be done. They chose not to treat the child.
>
> **Commissioner Destro.** Is it fair to say, then, that the decision not to treat was based on the fact that the child had Down's syndrome?
>
> **Dr. Owens.** I think it was, and all that this implied. In other words, that the gain, if you want to say this, that to go through all of this, to treat such a child with everything that's involved in that, and then to do all that with such a dreary, hopeless outlook as to the future, the parents felt this was not indicated either for themselves or the child.[30]

The significance of Dr. Owens' approach to the treatment of persons with disabilities was echoed in the statements of other witnesses, and therein lies the crux of the constitutional problem. It occurs in light of a history of discrimination against persons with mental disabilities that has been described by each Justice of the United States Supreme Court as "grotesque."[31] More important, what is at stake in denial of treatment cases is not merely "equal protection of the laws" but protection of life itself.[32]

Thus, when medical care decisionmaking is based on little more than personal experience and hearsay regarding the capabilities and problems of persons with disabilities and their families—that is, on deeply ingrained stereotypes that relegate persons with disabilities to a perpetually subordinate status—there can be no question that the equal protection clause forbids government action that either rests on such stereotypes or affirms them.

Procedural Due Process

The due process clauses of the 5th and 14th amendments require, among other things, that certain procedural protections must be provided before the government may deprive individuals of life, liberty, or property. Known as procedural due process, the doctrine is most frequently interpreted as providing an opportunity to be heard on the issue of the fairness and lawfulness of the proposed deprivation. The procedure required is determined by weighing several factors:

> First, the private interest that will be affected by the official action; second, the risk of an erroneous deprivation of such interest through the procedures used, and the probable value, if any, of additional or substitute procedural safeguards; and finally, the Government's interest, including the function involved and the fiscal and administrative burdens that the additional or substitute procedural requirements would entail.[33]

Disabled infants who are denied food, water, and medical care on the basis of their disability are denied both life and liberty. At a minimum, the 5th and 14th amendments require that they be afforded procedural due process, but in many of the cases brought to the Commission's attention, there was no procedural protection afforded at all. Potential advocates for the child were not identified and notified of the denial of treatment, nor were they given adequate opportunity to present the case for providing care that children without disabilities would be provided as a matter of course.

A thorough evaluation of the type of procedural protection that should be provided is beyond the scope of the Commission's inquiry, but the factors addressed by the Supreme Court in *Mathews v. Eldridge*[34] counsel that careful and informed evaluation of each case by independent and disinterested decisionmakers is required.[35] Evidence in the record supports a finding that the risk of erroneous determinations regarding the nature and extent of future disability is extremely high. The record also supports a finding that children have been deprived of treatment based on both uninformed and biased medical advice. Given the magnitude of the child's interest and the risk of error to life and health, no argument has been made that there even exists a substantial government financial interest that would preclude a hearing.[36] Instead, it has been argued that the private nature of most medical care decisionmaking, as well as the substantial deference accorded parents in the care and upbringing of their children counsels against government intervention on behalf of newborn children with disabilities.

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[30] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights,* 228–29 (1986) (vol. II).

[31] Cleburne Living Center, 473 U.S. at 438, 454 (Stevens, J., concurring), 461 (Marshall, J., concurring and dissenting in part).

[32] *See* Furman v. Georgia, 408 U.S. 238, 272 (1972) (Brennan, J., concurring) (the right to life is the "right to have rights").

[33] Mathews v. Eldridge, 424 U.S. 319, 335 (1976).

[34] 424 U.S. 319 (1976).

[35] See chaps. 10–13.

Factors Limiting the Rights of Newborn Children with Disabilities

Relevance of "Privacy"

Although the term "privacy" appears in several State constitutions,[37] it does not appear in the Constitution of the United States. As commonly understood in constitutional law, the term "privacy" refers to two distinct concepts: (1) the inviolability of one's person, home, or things from unreasonable governmental intrusions; and (2) individual autonomy or liberty with respect to certain matters important to one's person or the course of one's life (e.g., marriage, sex, childbearing).[38] The protection for the locational aspect of privacy is found in the 4th amendment,[39] whereas the due process clause of the 14th amendment[40] is generally held to be the basis of the rights of individual autonomy that the United States Supreme Court has recognized over the years.[41] It is in the latter sense—individual autonomy—that the term "right to privacy" is used in cases involving the right to refuse medical treatment for oneself or others.[42]

Control and Upbringing of Children

It has long been held that parents have constitutionally protected interests in the custody, care, and control of the upbringing of their children.[43] It is also well-settled that the government may override parental decisions when the life, health, or safety of the child is endangered.[44] The reluctance of courts to intervene in disputes involving parental authority over children is evident in several of the reported cases involving denial of medical treatment to infants and children with disabilities.[45] Nevertheless, the Supreme Court's concern for parental prerogatives has always been tempered by the recognition that there is broad legislative authority to protect children from the misguided, negligent, or harmful acts of parents.[46]

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[36] There are, in fact, existing mechanisms for such hearings. The question for present purposes is whether they should be required as a matter of procedural due process. See chaps. 10–13.

[37] E.g., Ariz. Const. art. II, sec. 8; Fla. Const. art. I, sec. 23 (1980) Wash. Const. art. 1, sec. 7.

[38] *See generally,* Whalen v. Roe, 429 U.S. 589 (1977).

[39] U.S. Const. amend. IV: "The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no Warrants shall issue, but upon probable cause, supported by Oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized."

[40] U.S. Const. amend. XIV, sec. 1: "nor shall any State deprive any person of life, liberty, or property, without due process of law;. . . ."

[41] *See, e.g.,* Meyer v. Nebraska, 262 U.S. 390 (1923) (autonomy to make educational decisions; invalidating State law which forbade teaching any language other than English); Griswold v. Connecticut, 381 U.S. 479 (1965) (autonomy of married persons to use contraceptives; invalidating State laws prohibiting the use of birth control devices); Roe v. Wade, 410 U.S. 113 (1973), *reh'g denied,* 478 U.S. 1039 (1986) (autonomy to choose abortion; invalidating State laws protecting the unborn). *But see* Bowers v. Hardwick, 478 U.S. 186 (1986), *reh'g denied* 410 U.S. 959 (1973) (refusing to recognize autonomy of homosexuals to engage in consensual sodomy, but reserving decision with respect to sodomy by married couples).

[42] *E.g.,* Am. Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 402–03 (D.D.C. 1983) (dictum). Another example is found in Rasmussen v. Fleming, 154 Ariz. 207, 741 P.2d 674, 682 (1987) in which the Arizona Supreme Court construed article 2, section 8, of the Arizona Constitution, which provides that "No person shall be disturbed in his private affairs, or his home invaded, without authority of law," to include the right of a competent adult to grant another a proxy to refuse medical treatment on the grantor's behalf should he or she become incompetent.

[43] *See, e.g.,* Smith v. Org. of Foster Families, 431 U.S. 816 (1977); Wisconsin v. Yoder, 406 U.S. 205 (1972) (education); May v. Anderson, 345 U.S. 528 (1953) (custody); Pierce v. Society of Sisters, 268 U.S. 510 (1925); (education); Behn v. Timmons, 345 So.2d 388, 389 (Fla. App. 1977) ("a natural, God-given right"); New Hampshire v. Robert H., 118 N.H. 713, 393 A.2d 1387 (1978). *See generally,* B.C. Hafen, *The Constitutional Status of Marriage, Kinship, and Sexual Privacy—Balancing the Individual and Social Interests,* 81 Mich. L. Rev. 463 (1983).

[44] *See, e.g.,* Prince v. Massachusetts, 321 U.S. 158 (1944) (child labor). In *In re* Rinker, 117 A.2d 780 (Pa. Super. 1955), for example, the court discussed the policy considerations supporting involuntary deprivation of child custody for neglect as follows:

> It is a serious matter for the long arm of the state to reach into a home and snatch a child from its mother. It is a power which a government dedicated to freedom for the individual should exercise with extreme care, and only where the evidence clearly establishes its necessity. . . .
>
> Under our system of government children are not the property of the state to be reared only where and under such conditions as officials deem best.
>
> The power of the juvenile court is not to adjudicate what is for the best interests of a child, but to adjudicate whether or not the child is neglected. *In re* Rose Child Dependency Case, 161 Pa. Super. 204, 208, 54 A.2d 297 (1947).

Accord Petition of Kauch, 358 Mass. 327, 264 N.E.2d 371 (1970). *Cf.,* In the Matter of Baby M, 109 N.J. 396, 537 A.2d 1227 (1988) (rejecting both the right of parental consent and an absolute right of procreational autonomy where important State and child interests are at stake.) *See generally,* Thomas, *Child Abuse and Neglect Part I: Historical Overview, Legal Matrix, and Social Perspectives,* 50 N.C. L. Rev. 293 (1972); Note, *State Intrusion into Family Affairs: Justifications and Limitations,* 26 Stan. L. Rev. 1383 (1974).

[45] *See, e.g.,* Bowen v. Am. Hosp. Ass'n, 476 U.S. 610 (1986); United States v. Univ. Hosp., 729 F.2d 144 (2d Cir. 1984); Am.

Parental Autonomy and Medical Decisionmaking

The testimony developed during the course of the Commission's two hearings on the protection of newborns with disabilities left no doubt that parental choice in medical decisionmaking is strongly influenced by attitudes and prejudices reflected in the suggestions of attending physicians, medical staff, and others close to the family, such as clergymen and other family members.[47] Parents generally strive to act in the best interests of their children, whether those children have disabilities or not, and seek out medical advice to assist them in the difficult decisionmaking process which surrounds any medical care decision of consequence.[48] Thus, the first situation described in the introduction to this chapter—fully informed parents who refuse consent to medical treatment that is either not useful or burdensome to their child—was not the subject of any part of the Commission's inquiry.

It is only when parents are alleged to be neglecting the child's health interests that the cause for governmental intervention on behalf of the child arises. To speak of parental or familial autonomy or "privacy" in such a situation would be to argue that governmental intervention is inappropriate even in the face of a charge of parental neglect. The fact that the child is born with a disability does not change the analysis.

The significant issues for constitutional purposes arise when parental or guardian refusal to consent to medical treatment for a person with a disability is not based on a medically defensible difference of opinion about the harmful or useless nature of the proposed treatment. Instead, it is based on either: (1) lack of adequate, accurate information about the disability itself; or (2) irrational or negative attitudes and prejudices about the quality of life of persons with disabilities generally, or of persons with similar disabilities.[49]

The record explicitly supports a finding that medical care decisions affecting persons with disabilities—particularly mental disabilities—are strongly influenced by a lack of adequate information about such important matters as rehabilitation opportunities, costs, and community support.[50] Physicians and medical personnel often do not provide the information parents need, and many times the information that is provided is simply wrong or out of date.[51] State child protective agencies have an educational intervention role to play in such cases.[52] In the small, but significant, number of cases that are also influenced by negative attitudes about persons with disabilities,[53] State refusal to intervene to protect their interests raise serious equal protection problems.

The medical neglect statutes discussed in chapters 5 and 7 address each of these concerns, and they need not be repeated here. The important point is that parental and legal guardianship rights to make medical care decisions for dependent persons are subject to government oversight on behalf of the dependent. There is simply no other way to protect a dependent's interests.

For purposes of making policy, however, the difference between an argument based on an alleged constitutional right to parental autonomy and one based on the common law or statutory right of parents or guardians to refuse medical treatment is that the autonomy argument is far broader. In a case asserting the common law or statutory right to refuse treatment, the best interests of affected individuals are the central issues, and appropriate guidelines can be written to protect both the parental or guardianship relationship and the interests of the child or ward. As a matter of common or judge-made law, such standards can be modified in whole or in part by legislation. Constitutional rights to privacy (autonomy), however, operate as limits on the power of the government to make any regula-

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Academy of Pediatrics v. Heckler, 561 F.Supp. 395 (D.D.C. 1983); Weber v. Stony Brook Hosp., 60 N.Y.2d 208, 456 N.E.2d 1186 (1983), *aff'g*, 95 A.D.2d 587, 467 N.Y.S.2d 685 (App. Div. 2d Dept. 1983); *In re* Phillip B., A Minor, No. 66103 (Super. Ct., Santa Clara County, Cal., Apr. 27, 1978), *aff'd*, 92 Cal. App. 3d 796 (1979), *cert. denied*, 445 U.S. 749 (1980).

[46] Parham v. J.R., 441 U.S. 584 (1979); Prince v. Massachusetts, 321 U.S. 158 (1944).

[47] See chap. 2.

[48] *Id.*

[49] See, *supra*, text accompanying notes 13-16 (distinguishing between actions based on "thoughtlessness and indifference" and those based on prejudice).

[50] See chaps. 2, 3, and 9.

[51] See chaps. 2 and 3.

[52] See chap. 10.

[53] See chaps. 1-4 and 9.

tions at all regarding the subject matter.[54] Decisions based squarely on constitutional concepts of parental autonomy reflect a policy position that seeks to remove the issues from legislative or executive competence altogether.[55] Such a proposition finds little, if any, support in the case law.[56]

"Substituted Judgment": The Right to Refuse Medical Treatment by Proxy

Often raised in denial of treatment cases is the right of an individual to consent to or refuse medical treatment. This right, however, is not absolute, even for a competent adult who seeks to refuse personal treatment.[57] It must give way in the face of important governmental interests in protecting others:

1. The preservation of life;
2. the protection of interests of innocent third parties (e.g., children and other dependents);
3. the prevention of suicide; and
4. the maintenance of the ethical integrity of the medical profession.[58]

In the case of newborns with disabilities, this interest manifests itself in the principle that parents and legal guardians may give or withhold consent to medical treatment for their children or wards, subject to the power of the government to prevent medical neglect.[59] By definition, an infant is incapable of making individual decisions or exercising autonomy. Thus, to the extent that courts might rely on the infant's asserted right to individual autonomy as the basis for parental decisionmaking,[60] such courts are operating in the realm of legal fiction.[61]

Issues of Cost

Because the issues in deprivation of treatment cases involve such a massive deprivation of life and liberty in the form of withholding food, water, and needed medical treatment, the cost of such treatment alone is an insufficient reason for denial of treatment. There is no question that the added financial and other burdens that a child with a disability may place on other members of the family are serious issues of social welfare policy,[62] but these burdens alone cannot justify deprivation of life through either design or neglect.

The Ability and Willingness of Courts to Provide Protection

Although the Supreme Court has held that persons with mental retardation are not entitled to the benefit of "heightened [judicial] scrutiny" when they complain of discriminatory treatment by the government,[63] the Court was motivated by concern that legislative and administrative judgments affecting persons with mental retardation involve sensitive policy judgments related to their needs.[64] The Court's deference to legislative judgment, however, places a particularly heavy burden on Congress and the State legislatures to protect the rights and interests of persons with disabilities by statute.

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[54] *Cf.* In the Matter of Baby M, 109 N.J. 396, 537 A.2d 1227 (1988) (holding that where important interests of the child are at stake, parental consent is not the determinative consideration; rejecting absolute right of procreational autonomy which would support an absolute parental discretion over the health and welfare of the child).

[55] *See, e.g., In re* Peter, 108 N.J. 365, 529 A.2d 419, 427 (1987) (decided on nonconstitutional grounds); *In re* Colyer, 99 Wash.2d 114, 119–21, 660 P.2d 738 (1983) (decided, in part, on constitutional grounds). For an interesting discussion of the relationship between the concepts of consent and constitutionally based privacy or autonomy, *see* In the Matter of Baby M, 109 N.J. 396, 468 n.16, 537 A.2d 1227 (1988).

[56] *See, e.g.,* Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52 (1976) (parents' statutory right to refuse consent to minor's abortion overridden on constitutional grounds); Prince v. Massachusetts, 321 U.S. 158 (1944) (State interest in health of children outweighs guardian's right to employ the child in a manner the State has determined to be harmful). *See also* cases cited *supra* note 55.

[57] *In re* Conroy, 98 N.J. 321, 346, 348–54, 486 A.2d 1209, 1222, 1223–26 (1985). *See also* Roe v. Wade, 410 U.S. 113 (1973) (rejecting absolute right to control one's body).

[58] *E.g.,* Brophy v. New England Sinai Hosp., 398 Mass. 417, 497 N.E.2d 626, 634 (1986). *See also In re* A.C., 533 A.2d 611 (D.C. App. 1987) *reh'g granted en banc,* 539 A.2d 203 (D.C. App. 1988) (protection of others); *In re* E.G., a Minor, 161 Ill. App. 3d 765, 515 N.E.2d 285 (1987) (prevention of suicide: right of minor to reject blood transfusion for religious reasons).

[59] See chap. 5.

[60] *See, e.g., In re* L.H.R., 253 Ga. 439, 321 S.E.2d 716, 722–23 (1984); *In re* P.V.W., 424 So.2d 1015, 1020 (La. 1982).

[61] *In re* Conroy, 98 N.J. 321, 486 A.2d. 1209, 1246 (1985) (Handler, J., dissenting).

[62] While it is also possible to argue that resource allocation issues affecting persons with disabilities should also be analyzed under the equal protection clause, such arguments are beyond the scope of the analysis presented here. There has been considerable debate among Supreme Court Justices concerning the propriety of using the equal protection clause to analyze eligibility criteria for social welfare programs. *Compare, e.g.,* San Antonio Indep. School Dist. v. Rodriguez, 411 U.S. 1 (1973) (guarantee does not prohibit classifications having differential impact on the poor), *with, e.g.,* Dandridge v. Williams, 397 U.S. 471, 521 (1970) (Marshall, J., dissenting) (when analyzing classifications affecting receipt of governmental benefits, a court must consider "the character of the classification in question, the relative importance to individuals in the class discriminated against of the governmental benefits that they do not receive, and the asserted state interests in support of the classification."). *See also,* Plyler v. Doe, 457 U.S. 202 (1982) (though guarantee does not prohibit classifications based on aliens' legal status, State refusal to permit undocumented alien children to attend public schools is invalid). The discussion presented here, however, deals only with denial of either treatment or legal protection usually available to all on the basis of simple need.

[63] Cleburne Living Center, 473 U.S. 432, 443 (1985).

State Action Issues

The obligations of decisionmakers whose actions are fairly attributable to the government[65] are governed directly by the Constitution. Among those whose actions are subject to scrutiny under the equal protection and due process clauses are: (1) Federal,[66] State, and local hospitals and their employees (including staff physicians when their decisions are governed by hospital policy),[67] even though the action in question is taken at the request of the parents;[68] (2) State and local child protective agencies; (3) Federal, State, and local agencies charged with the enforcement of laws prohibiting discrimination on the basis of disability; and (4) State and Federal courts.

Although the Supreme Court's "state action" jurisprudence has been described as a "conceptual disaster area" and "a 'doctrine' without shape or line,"[69] several of its holdings are relevant to questions involving discriminatory denials of medical care by physicians. First, and perhaps most important, substantial government funding or regulation of an institution, program, or activity will not transmute what is otherwise a private decision into one which "may be fairly treated as that of the state itself."[70] The key is whether the decisionmaker is acting in his or her private capacity. In *Blum v. Yaretsky,*[71] for example, the plaintiffs complained that physicians responsible for the discharge or transfer of medicaid patients were "state actors" because their activities were almost fully subsidized by government. The Court stated:

> [A]lthough the factual setting of each case will be significant, our precedents indicate that a state normally can be held responsible for a private decision only when it has exercised coercive power or has provided such significant encouragement, either overt or covert, that the choice must in law be deemed to be that of the state."[72]

Thus, while the facts in each case must be examined to determine whether or not physicians and other medical care personnel are chargeable with constitutional violations if they engage in discrimination in the provision of medical care,[73] it goes without saying that when State child protective agencies, civil rights enforcement agencies, and courts act or fail to act on the grounds that an individual has a disability, such acts or omissions are subject to examination under the equal protection clause. The more difficult question arises when the government knowingly acquiesces in private discrimination or deprivations of life and liberty.[74] There are circumstances where the Court has held that government inaction—declining to act to prevent private conduct—may constitute government action, particularly where there is some indication of public encouragement of the private conduct in question.[75] As the Supreme Court noted in *Palmore v. Sidoti:* "The Constitution cannot control such [private] prejudices, but neither can it tolerate them. Private biases may be outside the reach of the law, but the law cannot, directly or indirectly, give them effect."[76]

Conclusion

The record developed during the Commission's two hearings and continuing investigation demonstrates that there is a grave danger to the constitutional rights of newborn children in cases where food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. The principle of equal protection of the laws is offended when disability is the basis of a nontreatment decision. Procedural protection for the interests of both child and parents is often absent completely or is woefully inadequate to the task of sifting the facts.

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[64] See *supra,* text at notes 13–15.

[65] See *supra* notes 7–10.

[66] See *supra* note 3.

[67] *See, e.g.,* Johnson v. Sullivan, Civ. No. 85-2434 A (W.D. Okla., filed Oct. 3, 1985). *See also,* S. Paulus, *Suit Filed in Oklahoma Alleging Twenty-Four Infants Died After Being Denied Beneficial Medical Treatment,* 1 Issues in L. & Med. 321 (1986).

[68] Parham v. J.R., 442 U.S. 584, 606–07 (1979).

[69] C. Black, *State Action, Equal Protection and California's Proposition 14,* 81 Harv. L. Rev. 69, 95 (1967).

[70] Jackson v. Metropolitan Edison Co., 419 U.S. 345, 351 (1974) (extensive regulation); Blum v. Yaretsky, 457 U.S. 991 (1982) (State subsidy of more than 90 percent of the medical expenses of patients insufficient). "The ultimate issue in determining whether a person is subject to suit under [42 U.S.C.A.] § 1983 is the same question posed in cases arising under the Fourteenth Amendment: is the alleged infringement of federal rights 'fairly attributable to the state'?" Rendell-Baker v. Kohn, 457 U.S. 830 (1982), *citing* Lugar v. Edmundson Oil, 457 U.S. 922, 938 (1982). Section 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. § 794 (Supp. 1988), however, protects an "otherwise qualified handicapped individual" from discrimination or denial of benefits "solely by reason of his handicap,. . .under any program or activity receiving Federal financial assistance. . . ."

[71] 457 U.S. 991 (1982).

[72] *Id.* at 1004.

[73] Burton v. Wilmington Parking Auth., 365 U.S. 715, 722 (1961) ("Only by sifting facts and weighing circumstances can the nonobvious involvement of the State in private conduct be attributed its true significance.").

[74] *See, e.g.,* Deshaney v. Winnebago County Dep't of Social Services, 812 F.2d 298 (7th Cir., 1987) *cert. granted,* 108 S.Ct. 1218 (1988) (No. 87-154).

[75] *See, e.g.,* Reitman v. Mulkey, 387 U.S. 369 (1967); Shelley v. Kraemer, 334 U.S. 1 (1948).

[76] 466 U.S. 429, 433 (1984).

Since the Supreme Court's decision in *Bowen v. American Hospital Association,*[77] it has been clear that judicial action is insufficient to protect newborn children with disabilities. The task of protecting such children from discrimination and neglect, whether based on ignorance or outright prejudice, thus falls to Congress and to the State legislatures.

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[77] 476 U.S. 610 (1986).

Chapter 9

The Incidence of Discriminatory Denial of Medical Treatment

How frequently in contemporary America are people denied medical treatment for treatable life-threatening conditions, or life-preserving food and fluids, because they have disabilities? The answer to this question is of great importance. If discriminatory denials of treatment in general occur only in isolated and unusual instances, the need for any government intervention in treatment decisions might be questioned, especially the need for a Federal role. If it were the case that there was a significant incidence of such discrimination before the effective date of the Child Abuse Amendments of 1984,[1] but that since then the incidence had greatly shrunk, that might imply that the amendments themselves are adequate to address the situation and that they are being effectively enforced. Such conclusions would suggest that there is little need for a change in the status quo.

Suppose, on the other hand, the evidence shows that there has been a significantly high incidence of medical discrimination against children with disabilities that is part of a much larger pattern of medical care discrimination against people with disabilities generally, and that this incidence largely persists despite 3 years of experience under the Child Abuse Amendments. Such a conclusion would suggest a need to examine critically the current approach to implementing the amendments with a view to seeing how it might be improved and whether other instruments are needed to protect the medical treatment rights of children with disabilities.

Difficulties of Estimation

Any attempt to quantify denial of treatment, now or in the recent past, is subject to inherent limitations. When health care personnel and parents agree to reject a course of lifesaving medical treatment for a child with a disability, they typically do not announce it to the world at large or report it in those terms to statisticians or public officials.[2] There have been isolated instances of treatment denials being publicly announced in medical journal articles, including one article that reported decisions to withhold lifesaving treatment from a number of newborn children with disabilities at Yale-New Haven Hospital in the early 1970s[3] and another describing similar decisions at Children's Hospital of Oklahoma in the 1980s.[4] The physicians who authored these articles were crusading for open acceptance of denial of treatment practices by their fellow professionals.[5]

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[1] 42 U.S.C.A. §§5101–5103 (West Supp. 1988). The 1984 law, discussed in detail in chap. 7, established standards of treatment for children with disabilities in all States that receive Federal funds for their child abuse and neglect programs.

[2] Nor is it usually reported to others within the hospital, such as members of an infant care review committee. A study of such committees in 10 hospitals in eight cities found that only one "requires [committee] review of any case where withdrawal of life support is proposed." Office of Inspector General, Department of Health and Human Services, Infant Care Review Committees Under the Baby Doe Program ii (1987). The other nine review such cases only when there is disagreement between the treating physician and parents or "the treating physician requests advice." *Id.* Nor may incidence easily be estimated based on records from retrospective reviews of such instances. Only two of the committees studied have or are planning to have retrospective review of "selected" cases, although patient deaths may be reviewed by other quality assurance committees. *Id.* at 5.

[3] Duff & Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery,* 289 New Eng. J. Med. 890 (1973).

[4] Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele,* 72 Pediatrics 450 (1983).

[5] For example, the Oklahoma health care personnel stated: "[D]ocumented suffering. . .is not only reduced but prevented, if one is persuaded that death is preferable to life under certain

Disincentives to Whistle Blowing

Denial of treatment cases typically come to public attention only when a "whistle blower"—usually a health care professional[6] or a family member[7] who is convinced the denial of treatment is wrong—reports the matter to a public agency or other rights advocate.[8]

There are substantial disincentives to whistle blowing whether it takes place among health care personnel or in the general population. A recent study of whistle blowers by Donald and Karen Soeken found that all of those studied who blew the whistle in the private sector lost their jobs. One-fifth of those surveyed (who also included Federal Government employees) were without jobs at the time of the study; 86 percent had "negative emotional consequences, including feelings of depression, powerlessness, isolation, anxiety and anger"; and 80 percent had physical deterioration. Mr. Soeken, a psychiatric social worker with a doctorate in human development, concluded (as paraphrased by a reporter) that "[T]here is so much retaliation against known whistle blowers [because]. . .it is associated with cultural taboos against tattling."[9]

Mr. Soeken said there are seven stages of life for the whistle blower: discovery of the abuse, reflection on what action to take, confrontation with superiors, retaliation, the long haul of legal or other action involved, termination of the case, and going on to a new life. "The last stage is the most difficult to reach," he said, "and most [of] them don't reach it."[10]

Bill Bush, himself a whistle blower who was demoted, maintains a computer file on whistle blowers with 8,500 entries. "When individuals phone him with dark secrets he exhorts them to keep quiet unless they're independently wealthy. 'I want to emphasize this one thing,' he says. 'Whistle blowing is dangerous. I've seen people bloodied. And it's not going to get easier to do. Nobody wants a snitch.'"[11] Sociology Professor Myron Peretz Glazer, an expert on whistle blowers, observes, "They break the unwritten law of social relationships. . . .They break a norm—the norm of loyalty."[12]

These realities lead to the conclusion that counting the number of reported or publicized cases alone would underestimate the incidence of discriminatory denial of treatment. It is probable that such cases represent only the tip of the iceberg. It is necessary to turn, therefore, to methods other than counting the reported cases.

Surveys of Physician Attitudes

One method of judging the prevalence of denial of treatment is by examining the attitudes of treating physicians and other health care personnel. Although surveys of attitudes toward denial of treatment do not provide direct evidence of the number of actual cases, the statements of health care professionals do establish that a significant proportion of them would participate in denial of treatment in certain circumstances. Two surveys of pediatricians published in 1988 suggest that contemporary denial of treatment is not infrequent.

The November 1988 issue of the *Journal of Pediatrics* contains a report on a poll undertaken to learn how pediatricians would influence treatment

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circumstances. . .it is prima [facie] irresponsible to obtain knowledge about the results of surgery on high risk infants and then not to use the negative results in informing the parents and others of the consequences of surgery." *Id.* at 451, *quoting with approval* Fletcher, *Spina Bifida with Myelomeningocele: A Case Study in Attitudes Towards Defective Newborns,* in Decision Making and the Defective Newborn 281 (C. Swinyard ed. 1978).

[6] Health care professionals did so in the "Baby Jane Doe" case. *Lawyer Fights on For Baby Doe,* USA Today, Dec. 13, 1983, at 2A, col. 1.

[7] A family member did so in *In re* T.A.P., No. 03231186 (Milwaukee County, Wis. Cir. Ct. July 31, 1987), *rehearing* (Aug. 12-13, 1987), a case involving denial of surgery to a child with spina bifida. Telephone interview with Thomas C. Potter, Assistant District Attorney, Milwaukee County, Wis. (Nov. 25, 1988).

[8] Occasionally, unusual circumstances bring a case to public attention in other ways. In a Minnesota case, *In re* Steinhaus, No. J-86-92 (Minn. Redwood County Ct., Juv. Div. Sept. 11, 1986), *reprinted in* 2 Issues in L. & Med. 241 (1986), the child to whom treatment was being denied was in the legal custody of a child abuse agency (although the agency had placed him with his mother) because of previous abuse by his father. For that reason, the agency received information about the treatment denial. Telephone interview with Michael H. Boyle, attorney for Lance Steinhaus (Dec. 1, 1988). In the Idaho "Baby Ashley" case, the proposed denial of treatment evoked public attention and agency intervention because the child—whose disability was not initially apparent—was found in a trash can shortly after birth, an event that made the headlines and led to reporters' putting a spotlight on the case. Medical professionals openly deplored the public attention, and agency involvement focused on them because they believed that without the publicity treatment could have been quietly withheld. Telephone interview with James Baugh, Managing Attorney, Coalition of Advocates for the Disabled, *amicus curiae* in the case (Dec. 1, 1988).

[9] Farnsworth, *Survey of Whistle Blowers Finds Retaliation but Few Regrets,* New York Times, Feb. 22, 1987, at 22, cols. 1-5.

[10] *Id.* at col. 5.

[11] Kleinfield, *The Whistle Blowers' Morning After,* New York Times, Nov. 9, 1986, sec. 3, at 1, col. 2, at 10, col. 2.

[12] *Id.* at 10, col. 2.

decisions based on the presence of varying degrees of hydrocephalus in children born with spina bifida.[13] The subjects of the study were 604 Fellows of the American Academy of Pediatrics selected on a random basis from the membership. Of the 604 pediatricians contacted, 373 or 62 percent returned the questionnaires, although 56 were discarded due to incomplete information.[14]

The questionnaires were designed to determine what approach the doctors would take toward lifesaving treatment for children with spina bifida. Approximately half the physicians were asked about children with spina bifida but no hydrocephalus and those with both spina bifida and moderate hydrocephalus. The other half were asked about children with spina bifida but no hydrocephalus and those with both spina bifida and severe hydrocephalus.[15] On the survey form, doctors could indicate that they would encourage surgery, be neutral, or discourage surgery. If the child were their own, the doctors could obtain all possible care, could provide only supportive care, or could answer that they were not sure what they would do.[16]

The authors wrote: "Previous experience with physician surveys suggests that the responses to surveys tend to be conservative. . . .Thus the results of this study would be more likely to err on the less controversial side (treatment of all infants)."[17] Nevertheless, the results of this survey were significant: the presence of hydrocephalus (which the pediatricians perceived as related to mental retardation) would lead the doctors away from encouraging surgery toward discouraging surgery, a trend more marked as the degree of the hydrocephalus became more pronounced. If the child were the doctor's own, a similar trend toward choice of supportive care only, increasing with the degree of hydrocephalus, was evident. About a third of the doctors (34.2 percent) either would not know what to do or would provide only supportive care if the child were their own and only had spina bifida, with no hydrocephalus. If the same child were another's, 36 percent would be neutral or would discourage surgery. The percentage of doctors who would either not know what to do or would provide only supportive care almost doubled (to 62 percent) for their own child with the presence of moderate hydrocephalus. In the same circumstances, 55.1 percent would be neutral or would discourage surgery for the child of another. With the presence of severe hydrocephalus, 75.7 percent would not know what to do or would provide only supportive care for their own child (49.7 percent were certain they would provide only supportive care), and 75.1 percent would be neutral or would discourage surgery for the child of another.[18]

Another survey, this one answered by 49 percent of the membership of the Perinatal Pediatrics Section of the American Academy of Pediatrics during fall 1986, disclosed widespread hostility to the standards of treatment adopted by the Child Abuse Amendments of 1984 and their implementing regulations.[19] Sixty-six percent declared that the standards do not allow sufficient consideration of the parents' views, and 60 percent stated that they do not allow adequate consideration of the infant's suffering.[20]

An attitude that discourages treatment is sometimes inculcated in medical school. Pediatric residents at Baylor College of Medicine in Houston, Texas, were asked the following questions both at the beginning and at the end of their 3-year residencies:

> In which of the following situations would you employ heroic measures to save an infant's life; that is, would you resuscitate a child with:
>
> Minor birth defects (eg, skin tags, extra digits)?
>
> Major defects (eg, tracheoesophageal fistula, duodenal atresia)?
>
> Birth weight less than 1000 g?
>
> Severe defects (eg, congenital hydrocephalus myelomeningocele)?
>
> Severe mental defects (eg, anencephaly, known severe brain damage)?[21]

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[13] Siperstein, Wolraich, Reed & O'Keefe, *Medical Decisions and Prognostications of Pediatricians for Infants with Meningomyelocele,* 113 J. of Pediatrics 835 (1988). See chap. 1, notes 9 and 14, for descriptions of spina bifida and hydrocephalus.

[14] *Id.* at 837.

[15] *Id.* at 836-37.

[16] Siperstein, Wolraich, Reed & O'Keefe, *supra* note 13, at 836.

[17] *Id.* at 840.

[18] *Id.* at 837, table 1. Further discussion of the results of this survey appears in chap. 4, at the text accompanying notes 12-14.

[19] The standard of treatment the act and regulation require is described in chap. 7, at the text accompanying notes 42-102.

[20] Kopelman, Irons & Kopelman, *Neonatologists Judge the "Baby Doe" Regulations,* 318 New Eng. J. Med. 677, 683 (1988). The survey authors agree with the majority, arguing that death is in the best interests of some infants who must be given life-preserving treatment under the Child Abuse Amendments.

[21] Berseth, Kenny & Durand, *Longitudinal Development in Pediatric Residents of Attitudes Toward Neonatal Resuscitation,* 140 Am. J. Diseases of Children 766, 767, table 2 (1986).

Using a cumulative scaling procedure known as Guttman scoring, the authors were able to conclude that "residents demonstrated a significant increase in reluctance to resuscitate during the first year. . .of training. . .[and] a highly significant change during the third year. . . .Both periods of change demonstrated increasing Guttman scale scores, indicating that residents had developed attitudes during those time intervals of increased reluctance to resuscitate. . . ."[22] The authors attributed the increased reluctance to resuscitate to the assumption that "these residents may have been strongly influenced by faculty members and other role models who interacted with the residents."[23]

Turnbull Analysis

Apart from these recently published studies, the most comprehensive and well-documented evaluation that has been done to date appears in the statement prepared for the Commission by H. Rutherford Turnbull, professor of Special Education and Law at the University of Kansas. It has been included as appendix B to this report. In it, Professor Turnbull evaluated the available polls of health care personnel, summarized relevant sociological research, and surveyed the professional literature. What follows is a brief synopsis of Turnbull's paper.

Turnbull summarized earlier polls of attitudes among health care professionals, incidence data, and recent trends in the literature on medical ethics. He concluded that these demonstrated the existence of "a contemporary attitude in the medical profession that supports discrimination in medical care against children, particularly newborns with moderate to severe/profound disabilities" that "has been linked to unwarranted deaths" and that justifies Federal action to prevent such discrimination from occurring.[24]

Several polls have been conducted among pediatric surgeons, pediatricians, and nurses in neonatal intensive care units eliciting their responses to hypothetical treatment situations involving infants with medically correctable life-threatening conditions who were also at risk for mental retardation or other disability after the treatment. Approximately 77 percent of the surgeons and 50 percent of the pediatricians in a 1975 survey conducted by the Surgical Section of the American Academy of Pediatrics said that they would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia[25] if the infant also had Down's syndrome." Approximately 63 percent of the surgeons and 43 percent of the pediatricians indicated that in such cases they would also stop supportive services such as the provision of intravenous fluids and nasogastric suction.[26]

A 1977 survey of Massachusetts pediatricians revealed that 51 percent of them believed that a Down syndrome child with intestinal block, whose parents rejected surgery, should not be operated on.[27] Even of the 46 percent of pediatricians in this Massachusetts survey who would recommend surgery, only 40 percent (approximately 18 percent of the entire group) would obtain a court order for treatment of the infant.[28] Sixty-seven percent of those surveyed would not recommend surgery for a baby with severe myelomeningocele, while 60 percent of those who would recommend surgery would nonetheless acquiesce in a parental decision not to authorize it.[29]

A 1984 survey of nurses at neonatal intensive care units and intermediate care nurseries in Houston revealed the predominance of attitudes favorable to the denial of treatment to infants with disabilities. In this survey, approximately 71 percent of the nurses felt that nurses and physicians should never resuscitate an infant with severe mental disabilities (e.g., severe brain damage). For infants with such disabilities as myelomeningocele or congenital hydrocephalus, approximately 48 percent of the nurses said that nurses and physicians should only occasionally resuscitate, while approximately 13 percent of the nurses stated that infants with such disabilities should never be resuscitated.[30] Indeed, approximately 37 percent of the nurses in this study "felt that sometimes a doctor should act in such a way as to cause an infant's death," and approximately 31 percent of them indicated that the decision whether to treat a sick newborn child should be influenced by whether or not there are healthy children at home.[31]

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[22] *Id.* at 767. Unfortunately, the authors provided no breakdown of the percentage of residents unwilling to resuscitate for any of the particular conditions listed.

[23] *Id.* at 768.

[24] App. B.

[25] Intestinal obstructions may occur as frequently as 1 in each 1,500 births. R. Behrman & V. Vaughan, Textbook of Pediatrics 780 (W. Nelson 13th ed. 1987).

If a complete obstruction is not corrected promptly, the infant's condition deteriorates rapidly, with persistent vomiting, loss of weight, dehydration, and death, usually within a few days. Most cases of intestinal atresia and other obstructions of the intestines are susceptible to surgical correction. *Id.*

[26] App. B.

[27] *Id.*

[28] *Id.*

[29] *Id.*

[30] *Id.*

To test the view advanced by Dr. James Strain, former president of the American Academy of Pediatrics, that "shifts in attitude" in the medical community have resulted in more frequent treatment for infants with disabilities who have life-threatening conditions, making earlier studies obsolete,[32] Turnbull surveyed more recent medical literature expressing contemporary health care providers' attitudes toward appropriate treatment responses to the birth of newborn children with disabilities. He found such literature to be "overwhelmingly in favor of denying treatment to those deemed to lack a sufficient 'quality of life.'"[33] Turnbull quoted from nearly two dozen articles and books, all authored by physicians, to show the predominance in the contemporary medical community of the belief that a "low quality of life ethically justifies or even mandates letting some children with disabilities die. . . ."[34]

Turnbull focused on two examples reinforcing the conclusion that numerous unwarranted deaths of children with disabilities have resulted from the current hegemony of the "quality of life. . .over the equality of life" ethos in the medical community.[35] One was a study of the disparate treatment over a period of 6 years of two groups of individuals affected with a potentially life-shortening heart malformation. The prospects for successful surgical correction of this malformation decrease over time to the point of disappearance, making early action vital. The study found that all children with the heart malformation but without Down syndrome were referred for surgical correction or treatment at an appropriately early age. However, 10 out of 28 children who had both the heart problem and Down syndrome were not referred until they were beyond 1 year of age, with the result that half of these children with Down syndrome had deteriorated to the point that surgery for their heart condition could no longer be performed.[36]

The other example was the practice at Children's Hospital of Oklahoma in which a quality of life formula served explicitly as part of the basis for denying treatment to 24 of 69 infants with spina bifida, an approach that resulted in their death.[37] The Commission relies heavily on the material Turnbull assembled in assigning considerable weight to his conclusion that: "It is obvious that many health care professionals still feel that there are circumstances in which it is proper to deny medical care to children with disabilities. Overwhelmingly, these decisions appear to be based on the doctor's own opinion regarding the child's 'quality of life' after treatment."[38]

Investigative Reporting

Professor Turnbull's conclusion is supported by other evidence obtained by the Commission. The Commission received detailed testimony from a Pulitzer and Peabody award-winning investigative journalist, Carlton Sherwood. He described the approach taken by himself and the teams working with him, as well as their findings.

> Since 1983 I have authored three separate in-depth series dealing with so-called Baby Doe cases, two for television and one for print. Roughly speaking, I have devoted about 18 months of direct field research to the subject and perhaps another year of study on Babies Doe and the host of related medical, social, legal, and ethical issues.
>
> During the course of my research, I traveled to 28 States, visited 19 intensive care hospital nurseries, and interviewed more than 250 physicians, nurses, lawyers, hospital officials, and parents who, at one time or another, were directly involved in Baby Doe cases.
>
> In all, my research staffs and I reviewed upward of 700 cases where there was a probability that infants died as a result of decisions to withdraw medical treatment. From that number, we targeted 300 cases where there was an admitted or a high degree of certainty, based on first-hand eyewitness testimony, that nonheroic or extraordinary medical care had been withheld based solely on the real or perceived presence of a mental or physical handicap.

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[31] *Id.*

[32] *Id.* (statements of Dr. James Strain, former President of the American Academy of Pediatrics, which conducted the 1975 poll cited in app. B).

[33] *Id.*

[34] *Id.* Articles and books excerpted at *id.*

[35] *Id.* (phrase used by Dr. Robert M. Blizzard, Chairman, Department of Pediatrics, University of Virginia School of Medicine).

[36] *Id.* at 4–5; Sondheimer, Byrum, & Blackman, *Unequal Cardiac Care for Children with Down's Syndrome*, 139 Am. J. Diseases of Children 68 (1985).

[37] *Id.*

[38] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 45–46 (1986) (vol. II) (testimony of Carlton Sherwood).

> Of that 300 we targeted, approximately 120 cases were acknowledged outright, sometimes in writing, by the physicians who actually took part in the process. . . .
>
> On a secondary level, we were able to document through records and the supporting testimony of other physicians, nurses, and parents directly involved, an additional 27 incidents where beneficial medical care was withdrawn or withheld because of a real or perceived mental or physical handicap.[39]

Sherwood described "the attitude that these children are disposable" as "pervasive" among the pediatricians with whom his teams spoke.[40]

It is sometimes argued that in many instances in which treatment was denied to a child with a disability like spina bifida or Down syndrome, the real basis for denial was the existence of other anomalies or life-threatening conditions that severely complicated the case. This was a claim that Sherwood also frequently confronted.

> On several occasions, however, I was fortunate enough to have the medical records. . .and let me tell you what some of the other anomalies. . .were.
>
> According to the medical charts of one baby boy with spina bifida we looked at, there were the additional complications of a hernia and an ear infection, both of which went untreated.
>
> Another spina bifida boy also developed bronchitis, but because antibiotics might have saved his life. . ., none was prescribed to alleviate his chest congestion. He died.
>
> A Down's syndrome baby who had an esophageal atresia also suffered from a hernia and a kidney infection. This severely handicapped child died after 23 days; he died of [de]hydration which, I'm told, is a remarkable feat for any healthy baby.[41]

Testimony from People with Disabilities and Their Relatives

There is a strong impression among many people with disabilities that the medical profession in general is influenced by negative and inaccurate stereotypes about them. Ed Roberts, who uses a wheelchair and a respirator, testified: "Disability creates its own stigma, [its] own fear; people react to it in different ways, but most of it often manifests itself in prejudice. . . .The medical profession is among the worst in this area; they see the worst."[42] John Kemp, who also uses a wheelchair, presented a similar view:

> [A]s chairman of the Board of Access Living, an independent living center in Chicago, I work very closely with the CEO of that organization, who is a quadraplegic [sic] female. We regularly conduct training programs for the University of Illinois Medical School for the doctors and to-be doctors there, and we are continually astounded at the naivete of the medical profession regarding the rights of and services for disabled individuals. Her problems, if they are female in nature, are usually referred to a physical medicine and rehabilitation person only because of her quadraplegia, and this phenomenon continues to astound her and infuriate her. That is symptomatic of the medical community, and I would say I have heard this comment on numerous occasions dealing with people who are disabled, that the disability becomes the primary focus of the medical attention, when, in fact, they may be in need of medical services unrelated to their physical disability or mental disability.[43]

The Commission heard testimony reporting that physicians who diagnose muscular dystrophy around age 4 or 5 frequently describe it as a terminal disability, without revealing that if a respirator is used, the person might well live a normal lifespan.[44]

Mental retardation evokes similar responses.

> In a paper by Ann and H. Rutherford Turnbull on the ethics of early intervention, the authors talk about the parents of a profoundly retarded young man of 15 who were frequently asked by the physicians who were working with the. . .youngster, whether they really wanted to continue with kidney dialysis or blood transfusions.
>
> Would those physicians have asked such a thing, even dared ask such a thing of the parents of any other 15-year-old minor child without a disability? Of course not.[45]

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[39] *Id.* at 51–52.

[40] *Id.* at 48–49.

[41] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 103 (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability). *See also id.* at 176 (testimony of Prof. Irving Kenneth Zola, Department of Sociology, Brandeis University) ("I think the medical profession may be less well-equipped than other segments of our society to make judgments as to what is the quality of life. This is based on at least a quarter of a century of experience of teaching at medical schools and looking at. . .who ultimately becomes a physician and the training to which they are exposed.")

[42] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 123–24 (1986) (vol. II) (testimony of John Kemp, Director of Human Resources, National Easter Seal Society). *See also id.* at 132.

[43] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 107 (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability).

[44] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 127 (1986) (vol. II) (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

[45] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 8 (1985) (vol. I) (testimony of C.

Surgeon General Koop testified that most of the problems concern the child with mental retardation "who has a problem that will kill him without surgery. . . ."[46]

There was particular objection to the terminology often used by health care personnel. "The absurdity of calling disabled people of any age defective is like calling us cars and. . .there is an implied warranty that's been breached in some way. We're not products or appliances, we're people, and I don't think we're defective."[47]

Research by sociologist Dr. Rosalyn Benjamin Darling tends to confirm these impressions:

> [P]hysicians lack information about the experience of living with disability. They too have been exposed to societal stigma towards the disabled, resulting in attitudes like these expressed by pediatricians I interviewed: "It is hard to find much happiness in this area. The subject of deformed children is depressing. Other problems I can be philosophic about; as far as having a mongoloid child, I can't come up with anything good it does. There's nothing fun or pleasant. It's somebody's tragedy. I can find good things in practically everything, even dying, but birth defects are roaring tragedies. Death doesn't bother me, but the living do."[48]

Darling pointed out that physicians are traditionally trained to seek to heal, and that when a disability will persist in spite of lifesaving treatment, some do not feel rewarded. She quoted a pediatrician she interviewed: "I don't really enjoy a really handicapped child who comes in drooling, can't walk, and so forth. Medicine is here to perfect the human body. Something you can't do anything about challenges the doctor and reminds him of his own inabilities."[49]

The parent of a 24-year-old man who has mental retardation testified that in April 1986 she took him to an Ohio physician because he was experiencing severe side effects from medication: "[The physician] said it really wasn't important because he was mentally retarded. . . ."[50] She also described being on a panel with pediatric neurologists in Colorado in 1984 during which the physicians, when asked the conditions under which they would perform lifesaving surgery for any child, insisted that the criteria are different "when the child is mentally retarded."[51]

Recent Medical Literature

Another approach to determining the extent of the problem is to consider how pervasive articulated support for denial of treatment may be. The Turnbull testimony appended to this report documents with numerous quotations and citations his conclusion that in the recent medical literature the "commentary on the issue is overwhelmingly in favor of denying treatment to those deemed to lack a sufficient 'quality of life.'"[52]

When made aware of the legal requirements concerning discriminatory denial of treatment, health care personnel sometimes seem more interested in ensuring that no one finds out about their violations than in implementing them. After a case in Danville, Illinois, in which Siamese twins were initially denied surgery, food, and water until public exposure by a whistle blower led to criminal proceedings, the *American Medical News* quoted Dr. L. W. Tanner as saying, "[I]f hospital business had stayed within hospital walls, perhaps the state would never have been called in." The article went on to report: "Since the twins' birth, the hospital has intensified its courses on confidentiality, particularly for new employes, and has reminded physicians to be cautious when discussing cases when they might be overheard."[53]

Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

[46] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 133 (1986) (vol. II) (testimony of John Kemp, Director of Human Resources, National Easter Seal Society).

[47] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 181 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

[48] *Id.* at 181. *Cf.* Alexander, *Medical Science Under Dictatorship*, 241 New Eng. J. Med. 39, 45 (1949) ("The original concept of medicine and nursing was not based on any rational or feasible likelihood that they could actually cure and restore but rather. . .motivated by the compassion in alleviating suffering.").

[49] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 257–58 (1986) (vol. II) (testimony of Margaret Burley, Director, Ohio Coalition for the Education of Handicapped Children).

[50] *Id.* at 259.

[51] *See* app. B. It is noteworthy that, contrary to some suggestions, negative quality of life assessments continue to be given concerning those with Down syndrome and spina bifida, often characterized as the "easy cases." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 44–45 (1986) (vol. II) (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas).

[52] *Siamese Twins' Case "Devastates" MDs*, Am. Med. News, Oct. 9, 1981, at 1, 15–16.

[53] App. B.

Conclusion

Thus, the surveys of health care personnel, the analysis submitted to the Commission by Professor Turnbull, the results of investigative reporting, the testimony of people with disabilities and their relatives, and the repeatedly declared views of physicians set forth in their professional journals all combine to suggest the likelihood of widespread denials of lifesaving treatment to children with disabilities that have continued since implementation of the Child Abuse Amendments of 1984 on October 1, 1985.

Chapter 10

Child Protective Services Agencies and Enforcement of the Child Abuse Amendments of 1984

Principal enforcement responsibility for the Child Abuse Amendments (CAA) of 1984 resides with State Child Protective Services (CPS) agencies, the variously named entities that exist to administer each jurisdiction's child abuse and neglect laws.[1] Under current law, the fate of children with disabilities who are threatened with denial of lifesaving medical treatment, food, and fluids largely depends on how effectively CPS agencies carry out this responsibility.

Alternative avenues are scarce. Direct Federal efforts to prevent this type of medical discrimination to date have been stymied by the Supreme Court. Ruling in *Bowen v. American Hospital Association*, the Court enjoined the Federal Government from direct regulation and investigation, under section 504, of "instances in which parents have refused consent to treatment."[2] The ability of private organizations or individuals to mount legal challenges to denial of treatment is restricted because in many States there are severe limitations on private standing to challenge threatened denials of treatment.[3]

CPS Delegation of Investigative Responsibility

Forty-eight jurisdictions receive Federal funds from the Department of Health and Human Services under the Child Abuse Prevention and Treatment Act. A review of their policies and procedures has shown that, on their faces, the policies of 14 of these States explicitly abdicate to internal hospital infant care review committees or hospital staffs the authority to decide whether illegal denial of treatment is taking place when a report of suspected denial of treatment is received by the State agencies.[4]

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[1] Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14,878, 14,878 (1985).

[2] 476 U.S. 610, 625 n. 11 (1986). See chap. 6, text accompanying notes 109–135, and chap. 12, text accompanying note 65, for further discussion of this decision.

[3]
> In forty-four. . .jurisdictions. . .anyone may bring the matter to the court's attention. However, [12 jurisdictions]. . .place some limitation upon who may bring the matter to the court's attention. Even in the other jurisdictions, just because the matter may be brought to the court's attention by an attorney or his or her client does not mean that a hearing before a judge will necessarily be had. A little over half of the jurisdictions surveyed employ some type of petition screening process. . . .In some jurisdictions the state child protection agency investigates, in others the county attorney or district attorney. In yet others, a court staff person is charged with conducting the investigation. The investigator often has authority to dismiss the petition, allow the petition to be filed or "informally adjust" the matter.

National Legal Center for the Medically Dependent and Disabled, *The Medical Treatment Rights of Children with Disabilities* §8.01 (1987) (available from the Legal Services Corporation).

Federal regulations, however, require that State CPS agencies make the determination whether treatment is medically indicated under the Child Abuse Amendments. The existence of hospital-administered infant care review committees (ICRC) does not relieve a State CPS agency of its responsibility to investigate suspected cases of withholding of medically indicated treatment or to employ its legal authority to prevent such withholding:

> [T]he existence and activities of the ICRC do not amend the responsibilities under State law of medical professionals and the hospital to report to the child protective services agency suspected instances of medical neglect (including the withholding of medically indicated treatment from disabled infants with life-threatening conditions). . . .Although the child protective services agency and the ICRC are to be guided by similar principles and standards regarding the best interests of the child, the Department [of Health and Human Services] believes they have separate and distinct functions. The primary function of the ICRC in this context is to offer counsel to the attending physician(s), the hospital and the family to assure that the parents have the benefit of prudent, knowledgeable and professional evaluations, recommendations and services, consistent with appropriate medical standards, to assist them in making sound decisions regarding the welfare of their child. The function of the child protective services agency is to determine those circumstances in which the power of the State must be invoked to protect the infant, and then to take appropriate action to do so.[5]

Section 5103(2) of the Child Abuse Prevention and Treatment Act of 1978 provides: "In order for a State to qualify for assistance under this subsection, such State shall. . .provide for the reporting of known and suspected instances of child abuse and neglect;. . ."[6] The implementing regulations require that programs receiving Federal funds must provide for "[p]rompt notification by individuals designated by and within appropriate health care facilities of cases of suspected medical neglect (including instances of the withholding of medically indicated treatment from disabled infants with life-threatening conditions);. . ."[7] Subsection 1340.14(d) requires that "the State must provide for the prompt initiation of an appropriate investigation by a child protective agency or other properly constituted authority to substantiate the accuracy of all reports of known or suspected child abuse or neglect."[8]

Shortly after the adoption of the Child Abuse Amendments, Professors Nancy Rhoden and John Arras openly challenged hospital infant bioethics committees to "educate" local CPS agency personnel so that they "come to appreciate *all* of the morally relevant factors involved and will, accordingly, defer to the decisions made by parents, doctors, and committees, except in cases where the child's best interests are *clearly* being threatened." The objective of such "education" is to encourage hospital committees "occasionally [to] condone nontreatment in circumstances not contemplated" by the Child Abuse Amendments of 1984 and their implementing regulations.[9]

One State CPS worker told Commission staff that there had been "only one reported case in the 3 years I've been here. Of course, we hear through the grapevine from medical personnel of cases that go unreported."[10] A Florida administrator stated, "I suspect that these cases are occurring in the State of Florida, but that the hospitals are handling the situations appropriately—which is the best of all worlds, really."[11] An administrator for the District of Columbia declared that "all of these cases have been resolved at the hospital level and we have not been called in."[12]

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[4] Ala. Dep't of Pensions and Sec., I Family and Children's Servs. Manual, Pt. VII-53 (Rev. May 1988); Alaska Division of Family and Youth Services, Child Protective Services Policy Manual tits. 300. §5.045(c)(1) & (d)(1) (January 1987); Ariz. Dep't of Economic Sec. Policy 5-55-8.E.1 (May 1988); Del. Dep't of Servs. for Children, Youth and Their Families, Policy on Medical Neglect of Handicapped Infants at 2 (August 1986); Fla. Dep't of Health and Rehabilitative Servs., Health and Rehabilitative Services Pamphlet 175-1, §3.4.17 (July 1988); Ga. Dep't of Human Resources, Guidelines for Medical Neglect of Disabled Infants, Introduction, ¶3 (undated); Haw. Dep't of Social Servs. and Housing Policy Manual Ch. 1100.9.2 (June 1987); Memorandum from Sandy Hodge, Me. Child Protective Servs. Program Manager, to Regional Program Managers for Child and Family Servs. (incorporating Action for Child Protection Fact Sheet at 3, question 7) (Apr. 16, 1985); Mich. Dep't of Social Servs. Manual Bulletin, Children and Youth, No. 86-11 at 46 (Rev. Nov. 3, 1986); Nev. State Welfare Div. Serv. Manual §417.11(c)(4) (September 1985); N.M. Human Servs. Dep't., Social Servs. Div. Procedure §4.8.3.2.1. (Oct. 1, 1987); Wash. Dep't of Social And Health Servs., Div. of Children and Family Servs. Manual ch. 26.33 F.(5)(b) (March 1987); Memorandum from Rozella Archer, Director, Servs. to Families and Children, W. Va. Dep't of Human Servs. to Area Administ., Social Serv. Coordinators [and] Child Protective Servs. Supervisors, Child Protective Servs. Policy pt. 2 ¶2, pt. 3 (Aug. 28, 1986).

[5] *Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers To Establish Infant Care Review Committees,* 50 Fed. Reg. 14,893, 14,900–01 (1985).

[6] 42 U.S.C.A. §5103(b)(2)(B) (West 1983).

[7] 45 C.F.R. §1340.15(c)(2)(ii) (1987).

[8] 45 C.F.R. §1340.14(d) (1987). The entity being investigated is hardly a "properly constituted authority" to conduct the investigation.

[9] Rhoden & Arras, *Withholding Treatment From Baby Doe: From Discrimination to Child Abuse* 63 Milbank Mem. Fund. Q. 18, 47–48 (1985) (emphasis in original). Similarly, Thomas Murray had confidently predicted that the Child Abuse Amendments of 1984 and their implementing regulations would be of purely "symbolic" importance because in practice "the impact of the legislation and rule will be minimal." Murray, *The Final Anti-Climactic Rule on Baby Doe,* Hastings Center Rep., June 1985, at 5, 6–7.

When State CPS agencies do not delegate their authority to internal hospital committees, they sometimes delegate it to the same organized elements of the medical profession who have strongly objected to the Child Abuse Amendments. In Nebraska, the State CPS agency simply turned over principal responsibility for evaluating reports of such denial to the State chapter of the American Academy of Pediatrics.[13]

> On September 30, 1985, Dr. Kenton Shaffer, on behalf of the Committee on Maternal and Child Health of the Nebraska Medical Association and the Fetus and Newborn Committee of the Nebraska Chapter of the American Academy of Pediatrics, notified the Nebraska Department of Social Services (DSS) that an Ad-Hoc Resource Committee had been formed to offer assistance to DSS in evaluating cases of suspected medical neglect of infants born with a handicapping condition. . . .
>
> Gina Dunning, state director of the DSS, accepted this offer on October 8, 1985, and entered into an agreement. . . .The DSS will refer all reports to the Ad-Hoc Resource Committee, which will supply consultative services 24 hours a day, at no charge to the department.[14]

The Arkansas Department of Human Services, Division of Children and Family Services, seems to rely almost entirely for enforcement on the Arkansas Children's Hospital. The hospital has estimated it "treat[s] 90–95 percent of the 'Baby Doe' cases in the entire state."[15] The State agency even contracted with the hospital to provide training workshops for its own "agency attorneys and child protective service workers."[16] It worked with the hospital in developing its procedures, without input or consultation from disability groups.[17] The "independent" physician who advises the State agency about whether medically indicated treatment is in fact being withheld is also selected by the hospital.[18] In other words, in 90 to 95 percent of the cases, the hospital under investigation for medical neglect is permitted to name the "independent" medical authority who will rule on whether the course of treatment or nontreatment is proper.

Special Relationship Among CPS Agencies and Doctors

This widespread and remarkable readiness of CPS agencies to surrender their arms-length oversight responsibility concerning medical neglect appears in part to be rooted in the special relationship that has developed between CPS workers and many members of the medical profession. In dealing with traditional forms of child abuse and neglect, CPS agencies rely primarily on health care professionals for diagnosis and reporting. These include situations where the parents say "the child fell down the stairs" but the bones were in fact broken by the parents, or where the child has been neglected to the point of exhibiting "failure to thrive" syndrome. Medical witnesses before the Commission repeatedly emphasized this point. An attorney for the American Hospital Association (AHA) testified:

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[10] Telephone interview with Michelle Gore, CPS Specialist, Kentucky Department for Social Services (July 21, 1988).

[11] Telephone interview with Chris Christmas, Senior Human Services Specialist, Florida Department of Health and Human Services (July 25, 1988).

[12] Telephone interview with Carolyn Smith, Chief of Intake for Protective Services, District of Columbia Department of Human Services (Aug. 9, 1988).

[13] See chap. 6, and text accompanying notes 59–62, 70, for a description of the position taken by the American Academy of Pediatrics on government intervention to protect children with disabilities.

[14] Eggert, Shaffer & Bausch, *Baby Doe—The Saga Continues*, Neb. Med. J., April 1986, at 103, 103–104. Commenting on a draft of this report, the Nebraska Department of Social Services took issue with the "inaccuracy" of these statements, stating: "While this Committee of experts MAY provide consultation to the Department regarding planning for and intervention steps of the investigation, by no means has the '. . .state CPS agency simply turned over principal responsibility for evaluating reports of such denial to the state chapter of the American Academy of Pediatrics.'" Letter from Kermit R. McMurry, Director, Nebraska Department of Social Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 3, 1988) (emphasis in original). However, the letter concedes that cases "may require independent consultation from practicing, specialized physicians which are available to the Department under an agreement with the Committee on Maternal and Child Health of the Nebraska Medical Association." *Id.* Furthermore, the Nebraska "Central Office Procedures in Regard to a Report of Suspected Medical Neglect of an Infant Born with Handicapping Conditions" state that upon receiving notification of such a report CPS agency staff "will immediately contact a representative of the Ad-Hoc Resource Committee for consultation of the report" and that based on "discussion and consultation with the Ad-Hoc Resource Committee" the agency general counsel will be contacted for a legal opinion. These procedures do not make involvement of the Ad-Hoc Resource Committee optional; they make it mandatory. It is clear that the agency's reaction to any report is heavily dependent on the advice of the Ad-Hoc Resource Committee.

[15] Letter from Bobbie Ferguson, Acting Administrator, Child Protective Services, to Mr. Tommy Sullivan, Regional Director, Administration of Children, Youth and Services 2 (Apr. 10, 1986) (available in files of U.S. Commission on Civil Rights).

[16] *Id.* at 1.

[17] Telephone interview with Sandra Haden, Arkansas Department of Human Services, by Dr. Leon Bourke (June 10, 1987).

[18] *Id.*

> from the internal hospital's point of view, one of the reasons AHA participated in the Child Abuse Amendments—after filing suit, of course, on 504—was the fact there was a possibility of dealing with these difficult decisions by building upon existing collaborative relationships within the hospital between the social workers and the child protective agency people.[19]

The contrast between the receptivity of most CPS agencies to views from medical organizations—some of whose numbers were responsible for abuses the Child Abuse Amendments were enacted to curtail—and to views from disability organizations—the groups representing those whom the amendments were designed to protect—is striking. According to a survey conducted by the journal *Issues in Law and Medicine*, of 37 responding jurisdictions, 34 said that they had consulted with medical representatives in formulating their implementing procedures, while only 11 said they had consulted with disability groups.[20]

CPS agencies have clearly been anxious not to offend the physicians whose discrimination they are supposed to be preventing. When the law that became the Child Abuse Amendments of 1984 was first proposed, the CPS agencies' national lobbying organization, the National Council of State Public Welfare Administrators, opposed it in part because "the good working relationship between social workers and physicians could be jeopardized."[21] Any belief that the amendments would lead to the development of an oversight (let alone an adversary) relationship with the medical profession hardly seems to have been justified. One physician who testified before the Commission was openly confident that, despite the Child Abuse Amendments, CPS agencies would do little to question nontreatment decisions:

> In terms of the workings of the Child Abuse Amendments, many of us have long worked with people in child abuse. We're used to that system and we would be surprised if it were an overwhelmingly interfering system. That is to say, they have their hands full with child abuse in the community as it is, and one doesn't expect that they will be doing a lot of newborn investigation by and large.[22]

Indeed, in over a third (17) of the jurisdictions receiving Federal funding, the State CPS agencies told the Health and Human Services Office of Inspector General either that "Baby Doe funds could be put to better use on general child protective programs, medical neglect or other priorities identified by States" or that the "Baby Doe problem is too small to warrant special Federal funds or attention."[23]

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[19] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 54 (1985) (vol. I) (testimony of Mary Ahern, Attorney, American Hospital Association). *Accord* Testimony of Dr. James Strain, American Academy of Pediatrics ("We, the medical profession, have a good relationship with child abuse agencies in the State. We have worked closely with them in the past. Of course, the reporting many times of child abuse comes from physicians.") *Id.* at 45. Testimony of Evan J. Kemp, Jr., Director, Disability Rights Center ("I think there's a bit of a problem in basing too [many] resources in the child abuse statute. Basically those statutes were set up so that doctors could report on parents that abuse their children, and this situation is sort of the reverse. We're asking them now to report on doctors who are denying treatment, and I think this whole setup is bad for the protection of infants born with disabilities.") *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 36 (1986) (vol. II); testimony of Carlton Sherwood ("In my experience, the State child abuse. . .workers. . .work hand-in-glove with the local hospitals for child abuse reports; they're one and the same. Some of the State child abuse agencies actually have offices in the hospitals where they actually work right there so the physicians can report something. They know these guys, they work with them.") *Id.* at 61.

[20] Interview with Dr. Leon Bourke, *Issues in L. & Med.* (Nov. 30, 1987). All the jurisdictions which consulted disability representatives also consulted medical representatives. One additional responding jurisdiction indicated it "probably" had contacted disability representatives. Those responding on behalf of three other jurisdictions said either that the jurisdiction had consulted no one or that they didn't know who, if anyone, had been consulted. *Id.*

[21] Bopp & Balch, *The Child Abuse Amendments of 1984 and Their Implementing Regulations: A Summary*, 1 Issues in L. & Med. 91, 104 n.66 (1985).

[22] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 240–41 (1986) (vol. II) (testimony of Patricia Ellison, M.D.). Dr. Walter Owens, the physician in the Bloomington Infant Doe case, was on the same panel as Dr. Ellison. He immediately said, "I would endorse Dr. Ellison's statement completely." *Id.* at 241. *Cf.* testimony of Carlton Sherwood ("Why do you think the AMA and the rest of these organizations are willing to let the State child abuse agency come in and look at anything they want to but not somebody from HHS? They're friends. They work together. . . .") *Id.* at 61.

[23] Office of Inspector General, Department of Health and Human Services, Survey of Baby Doe Programs 11 (1987).

CPS Agencies' Failure to Comply with Federal Regulations

The delegation of significant investigational responsibility by watchdog agencies to those they are supposed to be watching is perhaps the most serious form of widespread noncompliance by CPS agencies with the medical discrimination regulations it is their duty to implement. It is not, however, the only one.

In direct contravention of the governing regulations, six States' CPS agencies have no written policy specifying the manner in which they would obtain medical records to investigate a report of medical neglect.[24]

In addition, Federal regulations require that State CPS systems must have the ability to obtain: "[a] court order for an independent medical examination of the infant, or otherwise effect such an examination in accordance with processes established under State law, when necessary to assure an appropriate resolution of a report of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life threatening conditions)."[25] Yet 10 States' CPS agencies have policies that fail to provide for securing an independent medical examination of a child with a disability about whom a report of a suspected medical neglect has been filed.[26]

The impression that some States pay little or no attention to the standards of treatment embodied in the Federal law and regulations is reinforced by the fact that 11 States' CPS agencies have policies that either misdefine the term "withholding of medically indicated treatment," do not define it at all, or define the term in such an abbreviated fashion as to invite ambiguity and uncertainty.[27] In fact, Utah's CPS agency went so far as to create a new exception. Under its procedures, medical treatment need not be provided when "in the treating physician's judgment. . .the treatment itself under such circumstances would be inhumane."[28]

A majority of the States reviewed are not even clear in their policies concerning who is covered by the standards of treatment in the act. The Child Abuse Amendments standard of treatment applies to "disabled infants with life-threatening conditions."[29] 45 C.F.R. §1340.15(b)(3)(i) (1987) provides:

> The term "infant" means an infant less than one year of age. The reference to less than one year of age shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age. In addition to their applicability to infants less than one year of age, the standards set forth in paragraph (b)(2) of this section [defining "withholding of medically indicated treatment"] should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability.

Twenty-four State CPS agencies have policies that either do not define the term "infant" or—in direct contravention of the governing regulations—define the term to encompass only infants of less than a year in age.[30]

CPS Attitudes to Treatment Principles

There have also been a number of indications that some State CPS agency personnel are unsympathetic to the principles of treatment embodied in the Child Abuse Amendments.

When a bill that, in modified form, would become the Child Abuse Amendments was first before Congress, the national organization which represents CPS agencies conceded that "child protective service agencies should appropriately intervene in cases where it is alleged that medically beneficial treatment is being denied to handicapped infants."

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[24] These States are Alabama, Arkansas, Connecticut, Georgia, Mississippi, and New York.

[25] 45 C.F.R. §1340.15(4)(ii) (1987). The term "independent" connotes an individual free from the influence, guidance, or control of another. A hospital's own physicians, such as those serving on its ICRC, therefore cannot qualify as an "independent" source for the CPS agency. Each State's CPS system must construct its own bank of independent medical consultants.

[26] These States are Arkansas, Connecticut, Florida, Georgia, Hawaii, New York, Mississippi, Oklahoma, Utah, and Washington. Missouri's CPS agency will secure a court order for an independent medical examination only if the parent(s) do not consent and/or the attending physician disagrees with the recommendation of the ICRC. Missouri Division of Social Services, Division of Family Services, Children's Section Special Child Abuse/Neglect Investigation Procedure: Baby Doe, A-7, ¶8 (Oct. 1, 1986) (available in files of U.S. Commission on Civil Rights).

[27] These States are Arizona, Iowa, Mississippi, Montana, New Jersey, New York, Oklahoma, Oregon, Utah, Washington, and West Virginia.

[28] Utah Division of Family Services, Department of Social Services, Division of Family Services Policy and Procedures for Implementation of "Baby Doe" Legislation Pt. II-B (3).

[29] 45 C.F.R. §1340.15(a) (1987).

[30] These States are Alabama, Alaska, Arizona, Delaware, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, New Jersey, New York, North Dakota, Ohio, Oklahoma, Oregon, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, and West Virginia.

Nevertheless, the organization opposed the bill, emphasizing that:

> Cases involving the denial of health care for handicapped infants should not automatically be defined as child abuse or neglect. These decisions are most often the result of difficult medical/ethical judgments made by both the parents and doctors, and not instances of willful abuse or neglect resulting from malice or ignorance.[31]

A 1987 Health and Human Services Inspector General's report found that personnel at 11 of 49 State CPS agencies took the position that "[b]ecause of medical and ethical issues involved, CPS responsibility for Baby Doe cases is not appropriate," and 10 others were unwilling to state whether they regarded such responsibility as appropriate or not.[32]

CPS agencies are largely staffed by social workers. A witness before the Commission, Mary Jane Owen, director of Disability Focus, Inc., reviewed the literature of the social work profession. Although she found articles that discussed how to help "so-called healthy families deal with the tragedy of having a flawed infant or child," she found no material giving any positive picture of life with disabilities or describing the maximization of the potential of people with disabilities.[33] Social psychologist Adrienne Asch testified:

> [S]ocial workers, like everybody else, are brought up in a culture that devalues people with disabilities. And there's no reason to think that they're not going to bring that devaluing right to their work and they say, "These poor parents, I really understand why they don't want to treat this child. It's not really child abuse. I don't care what the law says. It is really understandable. The child is going to be a great burden."[34]

Individual expressions of a negative attitude by CPS personnel toward the mission implicit in their responsibilities under the Child Abuse Amendments of 1984 are not hard to find. For example, when asked if there had been any reports of withholding of medically indicated treatment in Texas in the preceding year, the CPS administrator there replied, "Are you kidding?" and described the Baby Doe question as "a misunderstood issue caused by an extraordinary event in Bloomington, Illinois. This issue is primarily an issue related to parents' and physicians' decisions concerning treatment of the child—it is a medical issue, not a political issue."[35]

Similarly, when a court action was initiated in Oregon to prevent the starvation of a terminally ill child with a disability, the CPS reaction was hostile:

> Karen Green, a state assistant attorney general for the Children's Services Department, said the reaction to the intervention. . .was "outrage. . .that a family which had the trauma of having a deformed child in the first place should then be dragged into court and have it suggested that they are not being proper parents. . . .The people I have spoken to are unhappy," she said.[36]

Even in well-publicized cases, State CPS agencies have repeatedly been reluctant or unwilling to act to protect children with disabilities from denial of life-preserving treatment. In the original "Infant Doe" case in Bloomington, Indiana, the local CPS agency was appointed by the trial judge to act as the child's guardian *ad litem* for the purpose of considering whether to appeal from his ruling supporting the death of the child. The agency considered the case and declined to appeal it.[37]

The Connecticut CPS agency has an agreement for shared responsibility with the Connecticut Department of Health Services "with regard to coordination and consultation with health care facilities providing inpatient newborn care and response to reports of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions). . . ." Under that agreement, the health services department has the responsibility to "[r]eview and approve health care facility policies concerning the care of critically ill/handicapped newborns."[38]

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[31] *Statement of the Role of Child Protective Services Agencies In Cases Involving Denial of Health Care for Handicapped Infants,* Resolution of the National Council of State Public Welfare Administrators of the American Public Welfare Association, May 11, 1984, *cited in* Bopp & Balch, *The Child Abuse Amendments of 1984 and Their Implementing Regulations,* 1 Issues in L. & Med. 104 n.66 (1985).

[32] Office of Inspector General, Department of Health and Human Services, Survey of Baby Doe Programs 11 (1987).

[33] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 146 (1986) (vol. II) (testimony of Mary Jane Owen, Director, Disability Focus, Inc.).

[34] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 147–48 (1986) (vol. II) (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

[35] Telephone interview with David Brock, Child Protective Services Manager, Texas Department of Human Services (July 29, 1988).

[36] Hilts, *Brain-Damaged Baby Dies Amid Court Fight Over Treatment,* Washington Post, Apr. 23, 1983, at A2, cols. 1-5, col. 3.

[37] Telephone interview with James Bopp, Jr., Attorney for Robert and Shirley Wright, a couple who sought to adopt Infant Doe (Nov. 30, 1988).

[38] Connecticut Department of Children and Youth Services, Agreement Between the Connecticut Department of Health Services and the Connecticut Department of Children and Youth

In 1981 a State legislative committee asked the Connecticut Department of Health Services to investigate denials of treatment at Yale-New Haven Hospital and in other hospitals around the State after hearings the committee held, stimulated by the investigative reporting of the *Hartford Courant*, documented a pattern of such denial. That pattern included the starvation of children with Down's syndrome (in one case taking 23 days), the provision of lethal overdoses to parents to give to children with disabilities, and the falsification of death certificates to cover up such deaths.[39] Instead of acting to stop such practices, the agency responded with a report that took the following positions:

> Parents may have to choose between caring for a devastated infant and maintaining food, shelter and clothing for the rest of the family.
>
> No one reviewing or making these decisions will be able to ignore economic considerations of some kind.
>
> . . . .
>
> The state, acting through the legislature, should not attempt to define or interfere with medical practice;
>
> . . .The state, acting through the legislature, cannot establish ethical or moral standards for its citizens to observe, because of the enormous variety of personal feelings on the subject which are present in our society. Such laws would be ignored and ineffective. . . .[40]

Confronted with denial of lifesaving surgery to a child with spina bifida in Robinson, Illinois, the Illinois CPS agency acted to protect the child only under threat of a Federal lawsuit.[41] In the "Baby Jane Doe" case, not only did the CPS agency refuse to act, but it provided a letter to the attorneys defending the denial of treatment stating that the denial constituted "no credible evidence of neglect."[42]

Although some of the examples above of attitudes of CPS workers antedate the Child Abuse Amendments, there is little reason to conclude that such attitudes have changed dramatically, given people's general reluctance to change their views.

Conflict of Interest

CPS agencies are part of the State government, often in the same department that runs hospitals and other institutions that provide medical treatment to children with disabilities. This can create a direct conflict of interest for the CPS agency. The "Baby Jane Doe" incident is a case in point. Jane Doe was denied treatment at University Hospital of the State University of New York at Stony Brook. The State attorney general represented the hospital—arguing not only against treatment, but even against governmental investigation of the situation. Similarly, the Oklahoma CPS agency never investigated or acted to thwart the course of selective denial of treatment to children with spina bifida at Oklahoma Children's Memorial Hospital. As James Bopp, Jr., testified, it had a strong incentive not to do so:

> In the Oklahoma case. . .the Oklahoma child abuse and neglect State authority is the very same State authority that operates the hospital at which the children were denied medically indicated treatment. You then have a situation in which the two agencies which may be involved, one in denying medical treatment and the other in enforcing and insuring that medical treatment is provided, are within the same department of the State government. It is difficult to believe in that circumstance that child abuse and neglect agencies would take enforcement action against a hospital that is a member agency of its own State department.[43]

Conclusion

In sum, the close working relationship between some CPS personnel and members of the medical profession has resulted in the substantial failure of many State child protective service agencies to effectively enforce the Child Abuse Amendments of 1984.

Services Regarding Medical Neglect of Infants in Connecticut Health Care Facilities 1 (Oct. 9, 1985).

[39] See chap. 12 and text accompanying notes 12-33.

[40] Connecticut Department of Health Services, *Infant Death: Life and Death in Newborn Special Care Units*, 46 Conn. Med. 589, 594-95 (1982).

[41] Telephone interview with Robert D'Agostino, former Deputy Assistant Attorney General, Civil Rights Division, Department of Justice (Dec. 1, 1988).

[42] Letter from William Larson and Jane Raven, Suffolk County Child Protective Services, to Paul Gianelli (Nov. 7, 1983).

[43] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 156 (1986) (vol. II) (testimony of James Bopp).

Chapter 11

The Role and Performance of Infant Care Review Committees

The establishment of infant care review committees—internal hospital committees that consider instances in which life-preserving medical treatment is being or may be withheld from infants with disabilities—is encouraged by the Child Abuse Amendments of 1984,[1] as it was by the final regulations the Department of Health and Human Services issued under section 504.[2] A 1986 survey found that 51.8 percent of hospitals with either a neonatal intensive care unit or over 1,500 births annually had established such committees, and an additional 8.9 percent were in the process of forming them.[3]

Many maintain that using infant care review committees[4] for advice when denial of treatment is being considered is preferable to governmental involvement. Robert Weir makes a typical argument:

> Simply put, such a committee can work as the third stage of a four-stage process of decision making and review—consisting of parents, physicians, the committee, and the courts as a seldom-used final stage. The committee can function as an advisory board to pediatricians making difficult decisions in the neonatal intensive-care unit, an internal appeals and review board, and an institutional check on abusive practices. This procedural process is preferable to having moral decisions in neonatal intensive care units hamstrung by governmental regulations, and it will achieve basically the same end: the provision of medical treatment to handicapped newborns who need and will on balance benefit from such treatment.[5]

On the other hand, some disability rights advocates are skeptical about the effectiveness of such committees in protecting the medical treatment rights of people with disabilities. For example, Professor James Ellis told the Commission:

> [A]necdotal evidence suggests they are very hit-and-miss as to whether or not they effectively investigate cases that are like the ones that have been under discussion here, and there is anecdotal evidence to suggest that some of them have not been very effective. And to place all of our civil rights enforcement resources in such a hit-and-miss kind of mechanism when the stakes are so high for the kids involved is distressing.[6]

History

The genesis of these committees may probably be traced to suggestions made in a 1975 law review article by pediatrician Dr. Robert Teel.[7] The concept was given impetus the following year by the New Jersey Supreme Court in its *In re Quinlan* decision.[8] The court wrote that the establishment of such committees "would be protective to the hospital as well as the doctor in screening out, so to speak, a case which might be contaminated by less than worthy motivations of family or physician."[9]

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[1] 42 U.S.C.A. §5103 note (West Supp. 1987) (see generally chap. 7).

[2] 45 C.F.R. §§84.55(a) & (f) (1986) (see generally chap. 6, and the text accompanying notes 72–77).

[3] University of Connecticut Health Center, Pediatric Research and Training Center, National Collaborative Survey of Infant Care Review Committees in United States Hospitals 6 (1987) (available from American Academy of Pediatrics) [hereinafter National Collaborative Survey]. The survey, largely funded by the National Institute for Disability and Rehabilitation Research of the U.S. Department of Education, was conducted by the University of Connecticut Pediatric Research and Training Center and the American Academy of Pediatrics. It was sent to 870 hospitals in 48 States, of which 643 (73.9 percent) responded. *Id.*, app. D at 1.

[4] They are also frequently called "ethics committees" and sometimes "patient care review committees."

[5] Weir, *Sounding Board[:] The Government and Selective Nontreatment of Handicapped Infants*, 309 New Eng. J. Med. 661, 663 (1983).

[6] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 35–36 (vol. II) (1986) (testimony of Prof. James W. Ellis, School of Law, University of New Mexico).

[7] Teel, *The Physician's Dilemma: A Doctor's View: What the Law Should Be*, 27 Baylor L. Rev. 6, 8–10 (1975).

However, a study published in March 1983 concluded that as of that date ethics committees had "not been widely adopted as a means of handling medical ethical problems. Only 1 percent of the hospitals in this country. . .have such committees."[10]

Widespread advocacy and then implementation of ethics committees came only in reaction to the public outcry over the Bloomington Infant Doe case and the Federal response under section 504 the outcry evoked.[11] In November 1983, a journalist described the change in the medical community:

> Under assault from the federal government. . .the American Academy of Pediatrics (AAP) has quietly but significantly changed its position.
>
> In the last several months, the AAP has come forward to say that hospitals should establish ethics committees made up not only of hospital staffers but also of community members. These committees would establish procedures to review cases in which doctors and parents have decided to forego life-sustaining measures.
>
> "Historically, the American Academy of Pediatrics has been unwilling to allow outsiders to participate in the difficult decisions these newborns bring up," said Thomas Murray of the Hastings Center in Hastings-on-Hudson, N.Y., an ethics think tank.
>
> . . . .
>
> Yet, given recent government attempts to intervene in treatment decisions, the medical profession now views "the ethics committee route as the lesser of the evils," Murray said.[12]

In 1983 the ethics committee concept was championed by two important sources: the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and the American Academy of Pediatrics. In March 1983, the President's Commission issued its report, *Deciding to Forego Life-Sustaining Treatment.* While condemning the denial of lifesaving surgery to a child with Down syndrome[13] (in apparent reaction to the Bloomington Infant Doe case[14]), the President's Commission rejected resort to government enforcement of section 504 of the Rehabilitation Act of 1973 as contemplated by the then recently promulgated Department of Health and Human Services' "Baby Doe" regulations.[15] Instead, it proposed a process of internal hospital review, including the use of ethics committees:

> This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases [including] those in which a decision to forego life-sustaining therapy has been proposed because of a physical or mental handicap, as well as cases where a dispute has arisen among care givers and surrogates over the proper course of treatment.
>
> Such a review could serve several functions. . . .First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate. Such a review mechanism has the potential both to guarantee a discussion of the issues with a concerned and disinterested "representative of the public" and to insulate these agonizing, tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings.[16]

When it filed its legal challenge to the first set of "Baby Doe" rules, the American Academy of Pediatrics also promoted medical ethics committees as an alternative.[17] An article by Dr. Norman Fost, a member of the American Academy of Pediatrics' Infant Bioethics Task Force, which played a key role in proposing such committees, makes clear that they were designed less to enforce the treatment standards of the law than to protect doctors and hospitals from "intrusion" by the government or other outsiders:

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[8] 70 N.J. 10, 355 A.2d 647 (1976), *cert. denied,* 429 U.S. 922 (1976).

[9] *Id.* at 669. Other courts subsequently spoke with approbation of ethics committees, primarily in the context of cases of potential termination of treatment for older patients. *See, e.g., In re* Colyer, 99 Wash. 2d 114, 660 P.2d 738 (1983); *In re* Spring, 380 Mass. 629, 405 N.E.2d 115 (1980); Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417 (1977).

[10] Youngner, Jackson, Coulton, Juknialis & Smith, *A National Survey of Hospital Ethics Committees,* in President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment 443, 448 (1983).

[11] *See, e.g.,* Cranford & Doudera, *The Emergence of Institutional Ethics Committees,* L., Med. & Health Care, February 1984, at 13, 14.

[12] Herskowitz, *The 'Baby Doe' Dilemma: The Ethics of Life and Death,* Philadelphia Inquirer, Nov. 20, 1983, at 1D, cols. 1-2.

[13] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment 6 (1983) [hereinafter President's Commission Report].

[14] *Id.* at 224 & n. 92.

[15] *Id.* at 225-27.

[16] *Id.* at 227.

[17] American Academy of Pediatrics, News Release: Pediatricians Oppose Federal Rule on Handicapped Newborns 2 (Mar. 18, 1983) (available in files of U.S. Commission on Civil Rights).

> The theoretic basis for ethics committees is that they should be better able to emulate the "ideal ethical observer" than could any single individual. Even if they did not achieve this ideal, however, they might serve the following purposes.
>
> *Political.* They offer a mechanism for accountability that could avoid less desirable alternatives.
>
> *Therapeutic.* They offer a forum for nurses and others who are aggrieved by decisions to express their concerns and feel part of the decisionmaking process. This not only helps professionals who experience suffering, but it may avoid the whistle-blowing that leads to unwelcome publicity and intrusion.
>
> *Legal.* The risks of civil or criminal liability would presumably be fewer if the responsible physician could show his or her decision was reached after extensive consultation and deliberation. Consultation should reduce the chance of making decisions that create actual civil or criminal liability. It is also less likely that charges will be brought if decisions are seen as resulting from extensive consultation and deliberation. Even if charges are brought, the risk of conviction is reduced by demonstrating that due care was taken in making a decision.
>
> *Educational.* By increasing sensitivity within the institution, committees can presumably improve the ethical acceptability of complex decisions.[18]

Central to the rationale for reliance on such committees was the position, taken by both the President's Commission and the Academy of Pediatrics, that precise substantive rules about when treatment should be provided or withheld are inappropriate. The President's Commission argued that there are three categories of situations in which choices between provision and denial of lifesaving treatment are made: those in which treatment is clearly beneficial, those in which it is clearly futile, and a gray area in between.[19] The content of these broad categories was left deliberately vague. Beyond stating that treatment is clearly beneficial for those with Down syndrome, the President's Commission rejected the use of "[s]upposedly objective criteria [which] seems to remove the weight of responsibility too readily from those who should have to face the value questions—parents and health care providers."[20] In effect, the President's Commission concluded that because no hard and fast rules should be established for the gray area, the best approach to making appropriate decisions in individual cases would be to foster a process in which all information would be weighed by compassionate and knowledgeable individuals from a variety of backgrounds. This could best be achieved through the use of hospital ethics committees.

The American Academy of Pediatrics grounded its support for ethics committees in a similar analysis. "[I]t is impossible to develop a consensus on which infants within a broad range should be treated," the organization's president, Dr. James Strain, wrote. "The academy believes these difficult medical decisions should be made only after a thorough review, including consultation with a local medical review committee."[21] Dr. Strain emphasized that the committees should operate in the area of ambiguity: "It is the management of the. . .'in between' group where indications for unusual medical or surgical care are uncertain. . .which should be reviewed by an ethics committee at the local hospital level."[22]

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[18] Fost, *Treatment of Seriously Ill and Handicapped Newborns,* 2 Critical Care Clinics 149, 157 (1986) (emphasis in original). Dr. Fost's justification has been given in its entirety. Three out of four of the purposes described relate to fending off perceived threats to medical autonomy.

[19] President's Commission Report, *supra* note 13, at 217–23.

[20] *Id.* at 223. See the more detailed discussion of the President's Commission's approach in chap. 6 at the text accompanying notes 40–59.

[21] Strain, *AAP Will Fight Rule,* Milwaukee Sentinel, July 22, 1983, at 6, col. 5.

[22] Strain, *The Handicapped Infant,* AAP News and Comment, July 1983, at 15. The AAP developed guidelines for such committees. Infant Bioethics Task Force and Consultants, *Guidelines for Infant Bioethics Committees,* 74 Pediatrics 306 (1984) [hereinafter Infant Bioethics Task Force and Consultants]. Dr. Strain's perspective on the role of ethics committees did not change following the adoption of the Child Abuse Amendments of 1984. Addressing a December 1985 Colorado conference intended to examine implementation of the regulations issued under the amendments, he did not discuss the standard of care established by the amendments as the basis for committee deliberations, but rather repeated the view that treatment decisions fall into the categories of "clearly beneficial,. . .futile[,]. . .and that in which the burden of treatment must be weighted against the benefits—that 'gray area' of decisionmaking. Parents, physicians and IBCs will be called on to determine the best course of treatment." Strain, *Bloomington to Here: A Brief History of the Baby Doe Regulation,* in The Center for Applied Biomedical Ethics at Rose Medical Center, Medical Neglect and the Disabled Infant: The Impact of the Baby Doe Regulation 12, 14 (rev. ed. 1987).

From this perspective, as Carl Schneider has observed:

> [T]he wide range of deeply held opinions about neonatal euthanasia. . .presses us to take the problem. . .outside the sphere of substantive social rules by seeking ways to make decisions about neonatal euthanasia which do not require social conclusions about its underlying questions. Where there is pressure of this kind, the law. . .seeks procedural devices that obviate the need for substantive rules. For neonatal euthanasia, the nonsubstantive solution has commonly been to establish hospital committees to decide case by case whether neonatal euthanasia is appropriate.[23]

Thus, the proponents of ethics committees sought to shift the question from the substantive one of *whether* treatment should be withheld to the procedural one of *who should decide* whether treatment should be withheld.

As a substitute for HHS's proposed "Baby Doe" rule to implement section 504, the AAP submitted a detailed proposal for mandatory infant bioethics committees in each hospital.[24] Before promulgating the Final Rule, HHS conducted negotiations with the AAP, other medical groups, and disability rights groups, negotiations that soon focused on incorporating some modification of the AAP proposal.[25]

As a result of these discussions, the Final Rule included a recommendation that hospitals establish what HHS called "Infant Care Review Committees." However, HHS recognized that the original rationale for ethics committees stood in stark contrast to the approach embodied in the nondiscrimination tenets of section 504.[26] Inherent in reliance on section 504 was the assumption that the law establishes a societally defined basis for determining when life-preserving treatment must be provided to children with disabilities and when it may be withheld from them. In contrast, inherent in the original rationale for ethics committees was the assumption that such determinations should be decided on a case-by-case basis varying from hospital to hospital. Because of this dichotomy, the Supplementary Information published with the Final Rule explained that HHS had "revised the Academy's model somewhat to underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504."[27]

In the words of bioethicist Thomas Murray, a proponent of ethics committees and an opponent of the Final Rule:

> [A]lthough the hospital committee described in the rule is closely modeled on the one suggested by the American Academy of Pediatrics, its name has been changed from "Infant *Bioethical* Review Committee" to "Infant *Care* Review Committee"—substituting a medical for a moral term. And one type of member recommended by the Academy is absent from the HHS version—"the ethicist or member of the clergy."[28]

The 504 Final Rule was promulgated in January 1984. In October the Child Abuse Amendments of 1984 were signed into law. This legislation directed HHS to publish model guidelines for infant care review committees,[29] and when the Department did so in April 1985, the model guidelines were quite similar to those promulgated as a part of the Final Rule under section 504.[30] Before issuing the model rules, the Department had published interim model guidelines on December 10, 1984, and provided a 60-day period for public comment.[31] Responding to views expressed during this comment period by medical groups, the Department noted:

> Some commenters suggested a different name for the committee, such as "Infant Bioethics Committee" or some other term that emphasized the committee's function of considering questions of medical ethics. The Department has not changed the title of the committee because nothing in the authorizing statute corroborates the notion that the focus of the committee should be "medical ethics," at least to the extent that term connotes considerations different than those involved in evaluating medical treatment

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[23] Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 Calif. L. Rev. 151, 153–54 (1988). *See also* Fost, *Putting Hospitals on Notice*, Hastings Ctr. Rep., August 1982, at 5, 7 ("[T]he search for substantive criteria may be too difficult, and procedural safeguards may prove more serviceable. The government could, for example, require the establishment of a local review process, similar to the institutional review boards. . . .").

[24] *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1622, 1623 (1984) [hereinafter Final Rule (504)].

[25] Hilts, *HHS Moves to End "Baby Doe" Controversy on the Handicapped*, Washington Post, Aug. 24, 1983, at A2, cols. 1–5.

[26] The hospital ethics committee was understood by its proponents to be an alternative rather than a complement to enforcement of section 504. *See, e.g.*, Fleischman & Murray, *Ethics Committees for Infants Doe*, Hastings Ctr. Rep., December 1983, at 5, 6–8.

[27] Final Rule (504), *supra* note 24, at 1625.

[28] Murray, *At Last, Final Rules on Baby Doe*, Hastings Ctr. Rep., February 1984, at 17, 17 (emphasis in the original).

[29] 42 U.S.C.A. §5103 note (West Supp. 1988).

[30] *Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers To Establish Infant Care Review Committees*, 50 Fed. Reg. 14893 (1985) [hereinafter HHS Model ICRC Guidelines].

[31] *Services and Treatment for Disabled Infants; Interim Model Guidelines for Health Care Providers to Establish Infant Care Review Committees*, 49 Fed. Reg. 48170 (1984).

possibilities that "will be most likely to be effective in ameliorating or correcting" all life-threatening conditions.[32]

As contemplated by the model guidelines, "the basic policy [of infant care review committees (ICRCs)] should be to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions."[33] The Department envisioned that ICRCs would serve essentially as prognosis committees, marshalling and evaluating specialized medical opinion to determine whether the facts in particular cases placed them within the categories of the Child Abuse Amendments that require treatment or within the exceptions that make the provision of treatment (other than nutrition, hydration, or medication) legally discretionary.

Thus, the HHS guidelines assumed that the particular cases that came before a committee would not involve relitigation of the ethical and social debates about the propriety of treatment that preceded enactment of the law, but would instead focus on an analysis of how the law should properly be applied to the facts of that case. The "ethical issues" concerning what circumstances justify withholding of treatment were not to be up for reconsideration on a case-by-case basis; they were to be regarded as settled by the provisions of the Child Abuse Amendments.[34] Dr. Richard Barthel, chair of the Ethics Advisory Committee at Children's Hospital of Wisconsin, commented: "What does an ethics committee do at this point? Does it say, 'People, follow the law?' Then they put themselves out of business, frankly. Because the law is pretty clear. You probably don't have to debate many of these issues. . . ."[35]

Infant Care Review Committees in Action

Are the infant care review committees serving as prognosis committees, providing advice on whether or not the facts in particular cases bring them within the circumstances the Child Abuse Amendments define as requiring treatment as contemplated by the HHS model guidelines? Or do they act as "ethics" committees, making quality of life judgments about whether or not treatment should be withdrawn without reference to detailed legal standards—the role originally envisioned for them by the President's Commission and the American Academy of Pediatrics? A limited number of accounts describing the functioning of committees have appeared since the effective date of the Child Abuse Amendments.

A May 1986 article coauthored by the chair of the Children's Hospital of Wisconsin Ethics Advisory Committee described its functioning.[36] He and his coauthor advocated a model State statute that would give absolute and unreviewable authority to a unanimous hospital ethics committee (provided that parents and treating physicians agree) to choose to deny treatment to any newborn child "who allegedly has substantial physical and/or mental deficiencies that cannot be significantly cured or alleviated by surgery or other medical treatment."[37] This position is self-evidently closer to the President's Commission/AAP model than to the Department of Health and Human Services' model. Nevertheless, the authors stated that "[i]n making many of [its] determinations," the Children's Hospital committee "was guided by the Baby Doe regulations," which they then paraphrase, including this description of the third exception to required treatment: "treatment would be virtually futile in terms of the survival of the infant and, under the circumstances, inhumane."[38] However, in describing four cases in which the committee agreed with parents and treating physicians that life-preserving treatment should be withheld, they wrote: "In each case, the committee determined that the treatment either was futile, only prolonged the dying process, *or was inhumane and not in the best interests of the child.*"[39] This third category is far broader than the Child Abuse Amendments exception and effectively reintroduces a panoply of subjective judgments about the projected quality of life of a child with a disability.[40]

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[32] HHS Model ICRC Guidelines, *supra* note 30, at 14897.

[33] *Id.* at 14894.

[34] The HHS guidelines have no mandatory force. No hospital is required to establish an infant care review committee. Any hospital that does is not required to follow the Federal guidelines, nor will it receive any reward for doing so. HHS Model ICRC Guidelines, *supra* note 30, at 14893. However, to qualify for Federal funds, each State must have in place procedures that provide for prompt notification by health care facilities of suspected withholding of medically indicated treatment, as defined by the Federal standards. 45 C.F.R. §1340.15(c)(2)(ii) (1987). An infant care review committee following the President's Commission/AAP model instead of the HHS model would not report cases which the committee judged to be within the "gray area" and in which, upon consideration, it considered withholding of treatment ethically acceptable. If such withholding could be suspected of transgressing the Federal standards, this failure to report would violate the law.

[35] Address by Dr. Richard Barthel, Interpreting the Law: The Roles of the Hospital, Child Protective Services, and Legal System in "Baby Doe" Cases, Conference on 'Baby Doe' Ethical, Legal, and Child Protection Issues in Medical Treatment of Infants with Disabilities (Oct. 6, 1987) (videotape in files of U.S. Commission on Civil Rights).

[36] Shapiro & Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?* 37 Hastings L.J. 827 (1986). Dr. Richard Barthel chaired the committee; Robyn Shapiro is a bioethicist and attorney.

[37] *Id.* at 859.

[38] *Id.* at 855 n. 164. *Cf.* discussion in chap. 7, text accompanying notes 99–102.

The authors said the committee reviewed other cases "in which the parents, the physician, or other caregivers questioned whether the child's quality of life merited continued support or treatment."[41] In one such instance, the treating physician wanted to terminate ventilation for a child with congenital paralysis.

> The EAC [Ethics Advisory Committee] split strongly on the answer to this question because of the members' differing perspectives on the child's quality of life. Some felt that the child's inability to move and to communicate rendered the quality of his life negligible. Others felt unable to make such a judgment given the infant's age and the unpredictability of treatment outcome. Because the EAC could not reach a consensus, it advised continued ventilator support.[42]

On the basis of the facts given, it is hard to see even a colorable basis under the Child Abuse Amendments that would have justified denial of lifesaving treatment in this case.[43] Nevertheless, it was the subject of intense discussion and division on the committee. More to the point, even those supporting continued treatment did so apparently based only on their differing judgments concerning the child's projected quality of life—a factor emphatically excluded from consideration under the Child Abuse Amendments.[44]

In another case, "consultants" and "the majority of the nursing staff" wanted to terminate treatment for a child whose "prognosis included blindness, deafness, seizures, and negligible developmental potential."[45] The child's parents strongly supported continuation of treatment.

> The committee reached a consensus that further care was not ethically mandatory. There was a strong minority opinion that further care violated the child's best interests and that the mother's "abusive" stance should be reported and the case should be "taken to court." The committee's recommendations were entered into the child's chart, but there was no change in care.[46]

In this instance, it appears from the facts available that the committee supported denial of treatment that would have violated the standards of treatment in the Child Abuse Amendments.[47] There is no indication that the child was chronically and irreversibly comatose, that the treatment would have merely prolonged dying, that treatment would have been ineffective or otherwise futile in terms of the survival of the child, or that the treatment would have been "virtually futile in terms of the survival" of the child—a prerequisite to any legally valid consideration of whether "the treatment itself under such circumstances would be inhumane."[48] Had it not been for the insistence of the child's parents that treatment be provided, it seems evident that the committee would have sanctioned—and certainly not reported—denial of treatment of the sort now required by the law.

The committee did support treatment in two cases in which physicians and parents wanted to stop it and in all three cases in which parents wanted to stop it but physicians wanted to continue it, as well as in two cases in which the physician was uncertain.[49] Although the published record does not clearly indicate that the committee's deliberations actually resulted in the denial of treatment to any child in violation of the Child Abuse Amendments,[50] it does establish that during the period described in the article the committee gave consideration to factors impermissible under the Child Abuse Amendments. Rather than regarding itself as a prognosis committee with the role of making judgments about the medical facts and then applying the decided legal principles to them, it conducted itself, at least to some extent, as an autonomous ethical arbiter. In significant respects, therefore, the Children's Hospital of Wisconsin Ethics Advisory Committee appears in practice to have acted in a manner more closely approaching the President's Commission/AAP model than the HHS model.

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[39] Shapiro & Barthel, *supra* note 36, at 855 (emphasis added).

[40] See the extended discussion of this point in chap. 7 at the text accompanying notes 83–102.

[41] Shapiro & Barthel, *supra* note 36, at 854–55.

[42] *Id.* at 856.

[43] As with all the cases discussed, it is not clear whether this one occurred before or after the effective date of the Child Abuse Amendments. The article described the committee's functioning "over its three-and-one-half years of existence prior to the passage of the Child Abuse Regulations and during the six months following the law's implementation." *Id.* at 853. It is noteworthy that the authors made no mention of a significant change in the methodology of the committee during the last 6 months. Moreover, the article presented the committee's approach to the cases they describe as a model in general worth emulating, not as a methodology that should be radically altered in light of the entrance into effect of the Child Abuse Amendments.

[44] The HHS Interpretative Guidelines state: "*The Department strongly believes such an interpretation* [consideration of the infant's future 'quality of life'] *would be inconsistent with the statute.*" 45 C.F.R. Pt. 1340 App. Interpretative Guideline 9 (1987) (emphasis in original).

[45] Shapiro & Barthel, *supra* note 36, at 857.

[46] *Id.* at 857–58. Because the parents refused to accept the negative prognosis for their child, physicians went to the extent of ordering a psychiatric assessment of the mother. It concluded "that she was under stress but competent, well informed but unable to accept the medical information." *Id.* at 857. *Cf.* chap. 2.

[47] It is unclear, however, whether the case occurred before or after the Child Abuse Amendments of 1984 took effect in October 1985.

[48] 45 C.F.R. §1340.15(b)(2) (1987).

[49] Shapiro & Barthel, *supra* note 36, at 855–57.

The infant bioethical review committees of the Albert Einstein College of Medicine-Montefiore Medical Center affiliated hospitals have not only been the subject of published accounts,[51] but have also been held up as "a useful reference for hospitals considering the establishment of similar committees" by the HHS Inspector General.[52] Dr. Alan Fleischman, director of the Division of Neonatology and professor of pediatrics at the Albert Einstein College of Medicine and Montefiore Medical Center, has written about their operation. Although he noted and quoted the standards of treatment embodied in the Child Abuse Amendments,[53] he described the approach the committees take in language that could have come from the President's Commission report:

> We believe that the proper role of the ethics committee is to "decide who should decide"; that is, ethics committees should not. . .[arrogate] all decisions to themselves. . . .Our committee believes that there are three types of cases. First are those instances where treatment is clearly required based on the best interests of the infant and the future assessment of the benefits of that treatment. Second are cases where nontreatment is morally indicated—when infants are in the process of dying or when treatments would be clearly futile. Third are the cases where in our imperfect wisdom we honestly do not know what is in the best interests of the infant. This third "gray area" comprises a significant share of the morally problematic cases in newborn nurseries. . . .On these occasions when the principle of best interests of the infant cannot tell us what to do, we honor two other principles—respect for the autonomy of the family and letting those who bear the burdens make the choice; in other words, the parents who bear the burdens ought to make a decision consistent with the range of reasonable alternatives provided by the treating physicians. Thus, our ethics committee has agreed to differing outcomes in similar cases based on parental discretion within the range of the alternatives presented by the treating physicians.[54]

Fleischman stated that: "Although the federal regulations provided certain standards or guidelines, we have proposed. . .principles that might be utilized as the basis for decision making in complex cases and have found these principles to be helpful in deliberations and discussions at our infant bioethical review committee meetings."[55] Among those principles is: "Withholding or withdrawing treatment may be considered when such treatments are reasonably deemed futile and merely prolonging the dying process or when the medical treatment imposes a burden that lacks compensating benefits for the infant."[56]

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[50] With regard to the four reported instances in which the committee agreed with the physicians and parents that treatment should be withheld *(see supra* note 39 and accompanying text), the article is ambiguous about how many of the cases involved treatment that would merely prolong dying—a legal basis for termination of treatment—as opposed to circumstances in which life could be preserved but treatment was considered "inhumane" for quality of life reasons. It is also unclear which, if any, of these cases occurred after the effective date of the Child Abuse Amendments.

[51] Fleischman, *Bioethical Review Committees in Perinatology*, 14 Clinics in Perinatology 379 (1987); Fleischman, *An Infant Bioethical Review Committee in an Urban Medical Center*, Hastings Ctr. Rep., June 1986, at 16. *See also* Fleischman & Murray, *Ethics Committees for Infants Doe?* Hastings Ctr. Rep., December 1983, at 5 (describes "Neonatal Ethics Rounds" at Montefiore Medical Center that preceded formation of bioethical review committees and sets forth Fleischman's view of the purpose of such committees).

[52] Office of Inspector General, U.S. Department of Health and Human Services, Infant Care Review Committees Under the Baby Doe Program 11 (1987) [hereinafter Committees OIG Report]. Commenting on an earlier draft of this report, Montefiore Medical Center noted that personnel from the Office of Inspector General (OIG) "spent a full-day on-site. . .[at] Montefiore, in which OIG staff conducted case reviews and interviewed Committee members to get an in-depth understanding of the Committee's work." Letter from Nadia C. Adler, Vice President—Legal Affairs and General Counsel, Montefiore Medical Center, to William J. Howard, General Counsel, United States Commission on Civil Rights, at 5 (Nov. 11, 1988) *(reprinted* in app. D). Montefiore pointed out that the Inspector General's report stated that the Inspector General's report described the Einstein-Montefiore Committees as "generally structured and functioning in conformance with the HHS model guidelines." *Id.*, *quoting* Committee's OIG Report at 11.

In a letter commenting on the portion of chap. 12 critical of the Office of Inspector General for, among other things, praising the Einstein-Montefiore Committees in its report, the Inspector General wrote, "[Y]ou state that the OIG failed to review the facts in unreported cases considered by hospital infant care review committees. The purpose of our hospital visits was to determine how hospital committees are structured and functioning to deal with potential baby doe situations. It was never our intent to review actual case files." Letter from Richard Kusserow, Inspector General, to William Howard, General Counsel, U.S. Commission on Civil Rights 1-2 (Oct. 12, 1988). Referring to the draft's criticism of the Inspector General's report for describing the principles used by the Einstein-Montefiore Committees without pointing out their divergence from the standards required by the Child Abuse Amendments, the Inspector General wrote, "The purpose of this portion of the report was simply to serve as a reference to other hospitals considering the establishment of similar committees." *Id.*

[53] Fleischman, *Bioethical Review Committees in Perinatology*, 14 Clinics in Perinatology 379, 383 (1987).

[54] *Id.* at 387-88.

Commenting on an earlier draft of this report, Montefiore Medical Center asserted that these "principles are intended to assist the Committee members in applying the Child Abuse Amendments to the cases under review."[57] Emphasizing that the "Child Abuse Amendments and the regulations thereunder expressly defer to the 'treating physician's (or physicians') reasonable medical judgement,'" the center stated:

> In other words, Congress and HHS have made clear that the determination as to what, if any, treatment is medically indicated, is to be left to the professional judgment of the treating physician(s). Given that medical judgments are key to decision-making under the Child Abuse Amendments, it cannot responsibly be suggested that the Committee has violated the Child Abuse Amendments, simply on the superficial observation that medical treatment has been withheld.[58]

The center relied in particular on the HHS interpretation of the exception to a general requirement of treatment the Child Abuse Amendments create when "the treatment itself involves significant medical contraindications and/or significant pain and suffering for the infant that clearly outweighs the very slight potential benefit of the treatment for an infant highly unlikely to survive."[59] As the quoted passage makes clear, however, such benefits-burden balancing is legal only when the child is "highly unlikely to survive." The statutory language itself requires that "the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."[60] Although the law is phrased in the conjunctive, the principle Fleischman says the Einstein-Montefiore committees employ is phrased in the disjunctive: unlike the law, it allows treatment denial in cases of futility *or* under benefit-burden analysis.

From February 1984 through August 1986 (during the last 11 months of which the Child Abuse Amendments were applicable), eight cases involving withholding of life-preserving surgery from children "in the first days of life" were reviewed by the affiliated committees. (A total of 30 neonatal cases were reviewed; the article is not clear about the treatment/nontreatment outcome in the other 22 cases.) In one case in which the attending physician believed treatment should be provided and the parents disagreed, the committee referred the matter to the child protective services agency.[61] In a second case in which the treating physicians and parents believed treatment should be withheld, the committee considered that it should be provided, and both the physicians and parents were then convinced to agree to continued treatment.

In a third case the treating physicians wanted to deny treatment while the parents desired it to be provided; although the child died (presumably without receiving the life-saving surgery), the committee retrospectively concluded that "the parents' request was imposing undue pain and suffering on the infant for no potential benefit." In all the other cases the committee agreed with the desire of physicians and parents to withhold treatment.[62]

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[55] *Id.* at 384.

[56] *Id.* at 384–85. *But cf.* 45 C.F.R. §1340.15(b)(2) (1987) (definition of the Federal medical treatment standard of care barring "withholding of medically indicated treatment") (discussed in chap. 7).

[57] Letter from Nadia C. Adler, *supra* note 52, at 3.

[58] *Id.* at 7–8.

[59] *Id.* at 7, *quoting* 45 C.F.R. §1340.15 app. (1987). See chap. 7.

[60] 42 U.S.C.A. §5102(2)(B)(3) (West Supp. 1988).

[61] Montefiore Medical Center, commenting on this statement in an earlier draft, expressed concern that it implied the view "that the Einstein-Montefiore Committee took a neutral stance and was attempting to evade responsibility" when in fact the committee made the referral in order to override the parental refusal to consent to treatment. Letter from Nadia C. Adler, *supra* note 52, at 11. The Commission does not mean to suggest that the committee's action in this case implied neutrality; rather, in this case it is clear that the committee acted properly and fulfilled the responsibility to report imposed upon it by the law.

[62] Fleischman, *supra* n. 53, at 388–89. In its letter of comment, Montefiore says, concerning the third case: "As Dr. Fleischman's article plainly states, a retrospective review of the case (the infant was imminently dying and indeed died before the Committee could be convened for prospective review) indicated that the parents' wish to provide treatment would have imposed 'undue pain and suffering on an infant for no potential benefit.' *(Fleischman,* p. 389) The Report, once again, omits this detail." Letter from Nadia C. Adler, *supra* note 52, at 12. In fact, the Fleischman article at no point states that the child was imminently dying. If Montefiore is making this assertion based on its review of the medical records of the case, rather than on the article, then the denial of treatment would in fact not have violated the Child Abuse Amendments. However, what is striking about the description of the case in Fleischman's article, like that of all the other

Reviewing the first 30 months of the committees' operations, Dr. Fleischman concluded that "its existence had reversed the treatment decision for only one patient."[63] This did not lead him to consider, however, that the committees were not serving their function. Rather, he wrote:

> Since withholding or withdrawing of medical treatments is often carried out by the nurses with the consent and involvement of the families, review and confirmation of the appropriateness of this course of action by the ethics committee has made both nurses and parents far more comfortable with this aspect of the care of infants. . . .The psychological trauma of making a decision that results in the death of one's own child, we believe, may be greatly relieved by this decisional review process.[64]

The Commission emphasizes that in the absence of more detailed facts about the cases reviewed by the Montefiore committees from October 1985 onward, it is impossible to determine whether any of the treatment denials violated the standards established by the Child Abuse Amendments. However, Fleischman's article describes a set of committees that has been employing a balancing of "burden" and "benefit" standard that takes into account quality of life factors, rather than directly and explicitly applying the standards created by the amendments. Therefore, it seems a fair conclusion that the Einstein-Montefiore committees adhere more closely to the President's Commission/AAP model than to the HHS model.

The committee at University Hospitals of Cleveland has also been the subject of a published report.[65] The authors, who are associated with the committee, are quite open about their rejection of the HHS model:

> Although federal regulations have stimulated creation of ethics review committees their essential function is not adherence to government regulations but fulfillment of important needs within the hospital.
>
> . . . .
>
> Our approach differs. . .with the optional model [proposed by HHS]. . . .We prefer not to specify exceptions to the requirement to provide lifesaving treatment, because of concern that this might lead to oversimplification, neglecting unique aspects of individual cases. . . .We specify that the best interests of the patient are our primary concern in dealing with infant (or other incompetent) patients.[66]

The authors are frank in acknowledging that their criteria for treatment decisionmaking differ from those required by the law, but they claim they do not violate the "spirit" of the law when they conclude a child should be denied legally mandated lifesaving treatment as long as they consider death to be in the child's "best interests":

> *Committee recommendations are based on moral rather than legal. . .considerations. . . .*
>
> . . . .
>
> . . .If the committee, family, and physician recommendations are in agreement but the proposed medical action appears contrary to government regulations, the potential conflict should be communicated to the medical director or chairman of the pediatric department. Some may regard an action (or inaction) that runs counter to specific statutes as civil disobedience. Although civil disobedience is morally justified if a law is unjust, we do not claim that the new federal regulations are unjust. Rather, the regulations are open to alternative interpretations of what constitutes the best treatment for individual patients. . . .In other words, the spirit of the law supports the practitioners' obligation to promote the patient's interests in situations where literal observance may oppose it.[67]

It is evident from the article that the authors think one of the good effects of a functioning committee system is a decreased risk of government intervention. They report that on two occasions the committee was contacted by the Department of Health and Human Services because Baby Doe complaints had been received. "When the results of [committee deliberations] were reported to the Department. . ., no further investigation was judged necessary."[68] The authors suggest that "proceedings might have

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cases he details, is that the committee's reasoning is never described in terms of whether the cases fit within the categories established by the Child Abuse Amendments, but always in such ambiguous and amorphous terms as whether treatment or nontreatment would be "beneficial," or "appropriate," or in "the best interests of the infant," language largely popularized by the President's Commission's Report.

[63] Fleischman, *supra* n. 53, at 389. Fleischman believed that in the case referred to the child protective services agency, "it is highly likely that the same outcome. . .would have occurred prior to the existence of our infant bioethical review committee." *Id.*

[64] *Id.* at 389-90.

[65] Kliegman, Mahowald & Youngner, *In Our Best Interests: Experience and Workings of an Ethics Review Committee*, 108 J. of Pediatrics 178 (1986).

[66] *Id.* at 178-79.

[67] *Id.* at 180, 185 (emphasis in original). The idea of having hospital legal counsel on the committee was rejected because of "the desire to focus on ethical rather than legal matters, and concern that an attorney's presence might impede that purpose." *Id.* at 186.

[68] *Id.* at 183.

been initiated in at least the two cases reported anonymously to the federal government, had our committee not been in place."[69]

Public information about a fourth hospital committee places it in the pattern of the President's Commission/AAP model rather than the HHS model as well. St. Joseph's Hospital in Denver, Colorado, made a point of calling its committee an "Infant Bioethics Committee" rather than an "Infant Care Review Committee" in order "to stress that ours is a *human value*—not a legal—emphasis."[70] It also "decided early on not to include a lawyer, believing his/her presence could alter the human value course set by the IBC."[71]

What evidence is available from surveys suggests these four committees are not atypical. In September 1987, the HHS Inspector General published a report based on visits to ethics committees in 10 hospitals in eight major cities.[72] Although the HHS guidelines recommend that committee meetings be called whenever a preliminary decision has been made to withhold or withdraw life sustaining treatment from an infant with a disability in relevant categories,[73] 8 of the 10 committees visited had no such requirement.

In contrast, "All committees indicated they review cases involving disagreement between principal parties in the case (treating physician, parents, other hospital staff)."[74] The 1986 AAP/University of Connecticut survey found that of the ethics committees with prospective review, only 23.2 percent made it mandatory in certain cases—and only 61.7 percent of that 23.2 percent, or 14.3 percent of all committees with prospective review, required review in all cases in which treatment might be withheld or withdrawn from any infant.[75]

These are significant findings. It appears that the vast majority of committees convene only to deal with disagreements and do not attempt to scrutinize most denial of treatment decisions to see whether they comply with the law. This implies that many hospital infant care review committees seem more attuned to diffusing and resolving conflict in a way that keeps any controversy as much as possible within hospital walls than to ensuring that children with disabilities receive the lifesaving treatment to which they are entitled under the Child Abuse Amendments.[76]

Infant Care Review Committees and Reporting

Even before the passage of the 1984 amendments, the Federal regulations implementing the Child Abuse Prevention and Treatment Act required States receiving Federal funding for their child protective services programs to "provide by statute that specified persons must report and by statute or administrative procedure that all other persons are permitted to report known *and suspected* instances of child abuse and neglect to a child protective agency or other properly constituted authority."[77] The implementing regulations for the Child Abuse Amendments of 1984 establish that States receiving Federal funds must ensure that health care facilities designate individuals with the duty promptly to notify the State child protective services agency of all "cases of suspected medical neglect (including instances of the withholding of medically indicated treatment from disabled infants with life-threatening conditions)."[78]

Because not merely known but also "suspected" instances must be reported, the health care facility's obligation to notify the State agency is not limited to cases in which, for example, the infant care review committee or the responsible hospital official makes a final determination that illegal withholding of treatment is occurring or about to occur. Nor is it limited to cases in which the infant care review committee or the responsible hospital official has attempted to convince a parent or guardian to consent to legally required treatment but has failed and is turning to the civil authorities as a last resort.

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[69] *Id.* at 187.

[70] Infant Bioethics Committee, *A Demonstration by the St. Joseph Hospital IBC*, in The Center for Applied Biomedical Ethics at Rose Medical Center, Medical Neglect and the Disabled Infant: The Impact of the Baby Doe Regulation 25, 25–26 (rev. ed. 1987) (quoting Dr. Donald W. Parsons, chair of the Infant Bioethics Committee).

[71] *Id.*

[72] Committees OIG Report, *supra* note 52, at ii.

[73] HHS Model ICRC Guidelines, *supra* note 30, at 14895.

[74] Committees OIG Report, *supra* note 52, at 7.

[75] 65.8 percent of the 23.2 percent, or 15.3 percent of all committees with prospective review, required review in instances of withholding or withdrawing treatment from noncomatose infants. The rest of those who did make review mandatory did so in cases of disagreement among medical staff, or among medical staff and parents. National Collaborative Survey, *supra* note 3, at 44 (1987) (table 22).

[76] *Cf.* the rationale for such committees given by Dr. Norman Fost, *supra* note 18 & accompanying text.

[77] 45 C.F.R. §1340.14(c) (1987) (emphasis added).

[78] 45 C.F.R. §1340.15(c)(2)(ii) (1987).

Webster's defines "suspected" as "that one suspects or has a suspicion of. . . ."[79] "Suspicion" is defined as "imagination or apprehension of something wrong or hurtful without proof or on slight evidence."[80] By contrast, "known" is defined as something "that has become a part of knowledge <a truth that no one denies>."[81] Clearly, when there is enough question about an ongoing or contemplated withholding of treatment that an infant care review committee is convened to discuss it, there must be at least a "suspicion" that withholding of medically indicated treatment may be in prospect. The plain language of the applicable law would require a report.

Yet, it is evident that this is not the practice of most infant care review committees. The HHS Inspector General's report noted that of the "between 20 and 36 baby doe cases" considered by ethics committees at the 10 hospitals studied "since the regulations went into effect in October 1985," only 3 were reported to State child protective service agencies.[82] "Committee members pointed out that differences of opinion between treating physicians, parents and the committee can usually be resolved through an informal discussion process. *If this is not possible,* the hospital refers the case to CPS for investigation and possible legal action."[83]

These widespread failures to report are especially serious in light of the adoption by many hospital ethics committees of an approach that in general bypasses the Child Abuse Amendments standard of care in favor of the nebulous and subjective tripartite division of cases promoted by the President's Commission and the AAP. It means that there has usually been no independent review or investigation of what may have been—if the figures from the 10 hospitals contacted by the HHS Inspector General may be projected to the Nation at large—hundreds of potential Infant Doe cases since the Child Abuse Amendments went into effect in October 1985.

Limitations of Hospital Self-policing

It is questionable whether most committees are constructed in a manner that suits them to searching scrutiny of proposed denials of treatment. Infant care review committees, although they upon occasion have "outside" members, represent an approach to the "Baby Doe" problem that relies essentially upon the internal self-regulation of the health care community. Not only the Department of Health and Human Services,[84] but also the American Academy of Pediatrics,[85] recommended that committees include representatives of disability groups. But, as Adrienne Asch testified, in practice, a disability perspective is often unrepresented on the committees.[86] The 1986 survey found that of the responding hospitals, less than a quarter of their ethics committees—23.9 percent—had a representative of a disability group.[87] Instead, the committees are dominated by health care personnel from the institutions themselves. A practicing pediatrician serves on 86.6 percent of the committees, a practicing neonatologist on 75 percent, a practicing physician of another specialty on 80.2 percent, a practicing registered nurse on 88.4 percent, and a hospital administrator on 78.3 percent.[88]

Yet, a preponderance of medical personnel on committees does not necessarily mean that they are especially well equipped to serve as prognosis committees. As Dr. Mildred Stahlman testified, "[M]ost committees are not committees of experts in the medical field that the patient's problem lies."[89] In the words of George Annas, chief of the Health Law Section at the Boston University School of Public Health, "If consultation concerning the patient's prognosis is indicated,. . .a medical expert in the particular condition from which the patient is suffering should be consulted, not a committee of generalists."[90]

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[79] Webster's Third New International Dictionary of the English Language 2303 (P. Grove ed. 3rd ed. 1981).

[80] *Id.* at 2304.

[81] *Id.* at 1253.

[82] Committees OIG Report, *supra* note 52, at iii.

[83] *Id.* at 5 (emphasis added).

[84] HHS Model ICRC Guidelines, *supra* note 30, at 14894.

[85] Infant Bioethics Task Force and Consultants, *supra* note 22 at 307.

[86] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 144 (vol. II) (1986) (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

[87] National Collaborative Survey, *supra* note 3, at 35 (1987) (table 13). Even if local hospitals were to seek to broaden representation of disability groups, it is doubtful that such organizations have enough resources to provide adequate input into every individual hospital's ethics committee. It would be difficult to find an adequate number of disability rights advocates with up to date and accurate information on the treatment of every disability to cover every hospital in the Nation.

[88] *Id.*

[89] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 9 (vol. I) (1985) (testimony of Mildred T. Stahlman, M.D., Director, Division of Neonatology, Vanderbilt University). Dr. Stahlman opposed resort to committees not because she believed they are disposed to approve illegal denial of treatment but because she believed decisions about provision or denial of treatment should be left to "neonatologists [who are] their patients' best advocates." *Id.* at 5.

Many hospital ethics committees are largely insular bodies, sharing the mores and limitations of knowledge and viewpoint of the local hospital. A reluctance to criticize one's colleagues, let alone report their decisions to a State agency, is only natural in such a setting.

As Carlton Sherwood testified:

> Physicians and spokesmen from medical organizations frequently render offhand criticism of nontreatment incidents. Yet you'll note that not one physician or medical organization has ever formally or informally filed a complaint against any of the physicians who conducted these experiments, including Bloomington, Indiana.
>
> Indeed, rather than being censured, several of the physicians went on to more prestigious hospitals where they continue to practice medicine, and some even teach, presumably, the same methods that they were practicing when they authored these articles.[91]

Resort to infant care review committees, in short, presents the same problem generally applicable to the creation of an internal body as a means of showing the public that the institution is serious about correcting abuses: an institution rarely does a good job of policing itself. "Institutions and their staffs," Annas has written, "often see the primary function of ethics committees as protecting them against potential legal liability for treating or not treating particular patients. . . .Ultimately, it will be seen as unjust to have fundamentally different policies regarding the treatment of handicapped newborns at different hospitals. Policy in this area will have to be nationally based and thus consistent from one hospital to another. . . .[A]s soon as a national consensus does develop, it will not be fair or feasible for individual hospitals to ignore it and set their own idiosyncratic policies."[92] Outside oversight is needed.

Conclusion

Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments,[93] and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

At the same time, it is clear that such committees are here to stay. Therefore, the Commission believes there is a need to ensure that there be independent, contemporaneous scrutiny of infant care review committee proceedings, preferably by medically knowledgeable and experienced disability advocates, and that the prompt reporting requirement be more vigorously enforced to make this possible.[94]

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[90] Annas, *Ethics Committees in Neonatal Care: Substantive Protection or Procedural Diversion?*, 74 Am. J. Pub. Health 843, 844 (1984). After the New Jersey Supreme Court, in the Karen Ann Quinlan case, called for the use of hospital ethics committees to determine when life support systems should be withdrawn: "This was soon seen as an improper use of such a committee: the court found medical prognosis the determining factor, and only qualified physicians can make this determination. Thus New Jersey 'ethics committees' have been replaced by 'prognosis committees' made up entirely of consulting physicians." *Id.* at 843.

[91] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 47–48 (vol. II) (1986) (testimony of Carlton Sherwood).

[92] Annas, *supra* note 90, at 843, 845. Annas wrote before the passage of the Child Abuse Amendments of 1984, which established the national standards. Annas pointed out that, in contrast to the HHS model set forth in its section 504 Final Rule, the AAP model "tilts more in the direction of protecting the institution by keeping difficult cases out of court than of protecting the infant. . . .[U]nlike the Administration's proposal, the AAP proposal contains no substantive rules for the ethics committee to apply. . . ." *Id.* at 844.

[93] See chap. 9.

[94] See chap. 13.

Chapter 12

The Performance of the Federal Government

How well has the Federal Government fulfilled its responsibilities to ensure adequate enforcement of Federal laws that protect children with disabilities from discriminatory denial of medical treatment for life-threatening conditions? The two principal sources for Federal involvement have been enforcement of regulations issued under section 504 of the Rehabilitation Act of 1973[1] until they were struck down, and enforcement of the Child Abuse Amendments of 1984.[2]

Section 504

Responsibility for enforcing section 504 in this context rested with the Office for Civil Rights (OCR) in the Department of Health and Human Services until a final judgment and order was entered by the New York Federal District Court enjoining the final version of the "Baby Doe" regulations on June 11, 1984.[3]

In none of the cases OCR investigated—even the Bloomington Infant Doe case—did it officially determine that a violation of section 504 had occurred.[4] Standing alone, however, that observation is misleading. When it found a discriminatory denial of treatment, OCR asked for assurances that practices would be changed to achieve compliance with section 504 in the future. If it got them, it did not make a public "finding of discriminatory withholding of medical care."[5] Thus, in theory OCR might detect noncompliance in fact and secure remedial action by the discriminating party, thus fulfilling its role, without officially reporting a finding of noncompliance.

However, OCR has been criticized for failure to conduct prompt and effective investigations.[6] Of 150 cases OCR investigated from April 1982 through December 1983, only 31 were closed by the latter date—all with a finding of no violation or of insufficient information to investigate.[7]

It appears that members of the OCR staff assigned to Baby Doe investigations were unsympathetic to their enforcement duties:

> [C]ritics. . .within the department. . .say the government's policy violates family privacy and intimidates hospitals and their staffs.
>
> One department employee, who has been sent to investigate Baby Doe cases, called the assignment "probably the ugliest thing I've ever done," and added, "I never want to face another mother who is looking at me and saying, 'Why are you into my family business?'". . . .
>
> Another Baby Doe team member, who has almost a decade of experience in policing civil rights for the agency, said, "We never had a Baby Doe problem before this administration. It was beyond our imagination. It just came out of the blue from someone who has a very creative mind."

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[1] See chap. 6.

[2] See chap. 7.

[3] Am. Hosp. Ass'n v. Heckler, 585 F. Supp. 541 (S.D.N.Y.), *aff'd* 794 F.2d 696 (2d Cir. 1984), *aff'd sub nom.* Am. Hosp. Ass'n v. Bowen, 476 U.S. 610 (1986). See chap. 6.

[4] *Nondiscrimination on the Basis of Handicap;* Procedures and Guidelines Relating to Health Care for Handicapped Infants, 49 Fed. Reg. 1622 (1984).

[5] *Id.* at 1649.

[6] *See, e.g., Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 250 (1986) (vol. II) (testimony of Thomas Nerney, President, Disability Institute).

[7] Sherwood, *Baby Doe: The Politics of Death* 11 (1984) (Washington Times reprint).

> . . . .
>
> Department employees interviewed *all* said they had serious misgivings about the Baby Doe emphasis.[8]

Under the OCR procedures for Baby Doe investigations, medical consultants not unnaturally played a significant role.[9] Generally speaking, only an educated and experienced medical expert—not a lay investigator inexperienced in medicine or disability—can make the technical judgment concerning what medical treatment is necessary to preserve a particular patient's life. Effective investigations, therefore, necessarily depend upon the use of medical consultants who are competent and willing to make such a medical judgment in strict accordance with the nondiscrimination principles embodied in section 504.

OCR's selection of at least some medical consultants was surprising. They included Dr. Gordon B. Avery and Dr. George Little, both of whom submitted affidavits on behalf of the plaintiffs in the suit to invalidate the original regulations.[10] In a medical journal article, Dr. James Strain, the president of the American Academy of Pediatrics, revealed that during an investigation of alleged denial of treatment at Rochester, New York's, Strong Memorial Hospital in March 1983, the neonatologist flown in as OCR's consultant refused to examine the children concerning whom denial of treatment was alleged on the grounds that "the investigators had failed to obtain the parents' consent to examine the children."[11] Since the parents had presumably at least nominally acquiesced in the suspected denial of treatment, unilaterally giving them veto power over an investigation of the allegations was not a realistic way for the consultant to do an unbiased investigation of whether the allegations were substantiated.

Significant delays prevented efficient enforcement in investigations of substantial and notorious denial of treatment practices in Connecticut and Oklahoma.

Perhaps the first public acknowledgement of regular denial of lifesaving treatment to children with disabilities concerned Yale-New Haven Hospital. In 1973 Yale-New Haven pediatrician Raymond S. Duff coauthored a medical journal article revealing that 14 percent of a series of 299 deaths in the hospital's Newborn Special Care Unit were caused by deliberate withholding of life-preserving treatment, and providing a defense of the practice.[12]

In June 1981, the *Hartford Courant* published a series of articles by medical reporter Diane Brozek describing the continuation of the practices that had been set forth in 1973.[13] "Doctors at Yale-New Haven Hospital's Special Care Unit routinely offer parents the option of letting newborns with spina bifida die by withholding food and the surgery needed to close the baby's lesion to prevent infection," she concluded.[14] She recounted a number of specific instances presenting prima facie violations of section 504 as it was being publicly interpreted by the Departments of Justice and Health and Human Services:

> - [Michael Renfrew had brain damage resulting from a hemorrhage shortly after his birth. T]he doctors recommended more than once that Michael be allowed to die. [His father] Douglas Renfrew couldn't bring himself to make the decision. He remembered telling the medical team that multiple [sic] handicapped children deserve to live "if only because they teach us to value life."

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[8] Cimons and Green, *U.S. Moves in Baby Doe Cases Stir Anger*, Los Angeles Times, Nov. 12, 1983, at A1, col. 4, A6, col. 2 (emphasis added). *See also Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 250–51 (1986) (vol. II) (testimony of Thomas Nerney, President, Disability Institute) (Department of Health and Human Services probably has many physicians who "make arguments about the primacy of the medical profession").

[9] *See, e.g.*, Office for Civil Rights, Department of Health and Human Services, Discrimination Against Handicapped Infants by Withholding Treatment or Nourishment: Interim Expedited Procedure 3 (March 22–25, 1983) (included as Attachment 4 to Affidavit of Betty Lou Dotson, Am. Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983)).

[10] *See* Office for Civil Rights' Medical Consultants, attachment to Affidavit of Nathan D. Dick, Affidavit of George A. Little, M.D., attachment to Plaintiff's complaint for Declaratory and Injunctive Relief, Statement of Points and Authorities in Support of Complaint for Declaratory and Injunctive Relief (filed Mar. 18, 1983), and Affidavit of Gordon B. Avery, M.D., Exhibit A to Defendant's Deposition of Gordon B. Avery, M.D. (Mar. 30, 1983), Am. Academy of Pediatrics v. Heckler, 585 F.Supp. 541 (S.D.N.Y. 1983) (Civil Action No. 83–0774).

[11] Strain, *Special Report: The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, 309 New Eng. J. Med. 443, 444 (1983).

[12] Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 New Eng. J. Med. 890 (1973).

[13] Brozek, *Defective Newborns Are Dying By Design*, Hartford Courant, June 14, 1981, at 1, col. A1; Brozek, *At Issue: A Productive Life or Tragedy*, Hartford Courant, June 15, 1981, at A1, col. 1; Brozek, *Siamese Twins Case a Test of Infant Care Practices*, Hartford Courant, June 16, 1981, at A1, col. 3; Brozek, *Parents Chose Death for Baby*, Hartford Courant, June 17, 1981, at A1, col. 1.

[14] Brozek, *At Issue: A Productive Life or Tragedy*, Hartford Courant, June 15, 1981, at A1, col. 1.

> The baby's doctor, E. Laurence Hoder, agreed to continue care, but the infant died January 27. When the baby's heart began failing that night, Renfrew finally agreed by phone to disconnect a respirator so Michael could die. . . .[15]
>
> • [When Eric Scuterud was born with spina bifida at Yale-New Haven hospital in 1980, his parents] were told they could go ahead with the lifesaving operation and then institutionalize their baby. The doctors also gave the couple the option of letting the baby die by withholding food and the surgery that would close the back lesion to prevent infection.
>
> . . . .
>
> Doctors offered to let Eric go home to die, with an adequate supply of morphine to sedate him. . . .
>
> Doctors also told Honey Scuterud she would not be feeding him.[16]
>
> • Dr. Richard A. Ehrenkranz, on staff at the Yale-New Haven unit, said doctors there almost always abide by parents' decisions, whether for life or death.
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> . . . .
>
> . . .Ehrenkranz said the staff doesn't intervene to save a child against his parents' wishes, even when the child has a reasonable chance to survive with treatment. "Some medical institutions choose to step in, through the courts," he said. "We do not."[17]
>
> • [Although o]verdose deaths at Yale-New Haven are "infrequent,". . .a doctor there said[, in some cases] he and other doctors suggested the option, assuring parents they would sign the death certificate, no questions asked.
>
> The parents, he said, ended their infants' lives with morphine or phenobarbital prescribed by the doctors and usually dissolved in a baby bottle.[18]

In reaction to the *Courant* series, the Connecticut Senate Public Health Interim Study Committee on Medical Treatment for Newborn Infants began a series of hearings, chaired by Senator Regina Smith. At those hearings, "Dr. Joseph B. Warshaw, director of newborn services at Yale-New Haven, said that 'two or three times' in the last five years, infants with Down's Syndrome. . .were not treated for intestinal blockages that prevented them from digesting food."[19]

Dr. Raymond S. Duff testified:

> [I]n light of religious, personal, and family values and circumstances, some medical conditions are estimated to involve such a destructive impact on the family and often on the child as well that rescue seems unwise. Family and health professionals in these situations believe that tragedy will only be compounded for everyone if rescue is attempted.[20]

However, the committee received evidence that these judgments seemed at times to be less those of the family than those of Dr. Duff. For example, concerning his son James, born with cerebral palsy at Yale-New Haven Hospital in 1975, Leo Arria wrote Senator Smith:

> Even after realizing that James may not be normal we decided that as long as he was alive we wanted to do everything we possibly could do for him. It was then that we were called into conference with a Doctor Duff, who we were told was the head of Pediatrics for the hospital. Doctor Duff told us that James was going to be a great burden to us throughout our lives. He also told us that James would be a vegetable and a helpless human being. He told us to consider very seriously abandoning the child.[21]

Theodore and Cheryl Mekdeci wrote Senator Smith that their daughter Kimberly was born with spina bifida in 1975:

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[15] Brozek, *Defective Newborns Are Dying By Design*, Hartford Courant, June 14, 1981, at A1, col. 4.

[16] *Id.* at A25, cols. 2–3. Mrs. Scuterud felt she could not face the prospect of starving her child at home:

> "That was the one thing I know I couldn't do, not in my house," she recalled. The couple ordered the surgery, hoping the doctors were right when they said Eric probably wasn't brain damaged.

Id. at A25, col. 3. In 1981 Brozek wrote, "Eric Scuterud is intellectually normal for a year-old baby. He is quick with a grin and flirts with strangers by throwing kisses with a loud smack of his lips." *Id.* at A25, col. 1.

[17] *Id.* at A25, cols. 3–4.

[18] *Id.* at A1, col. 3. Brozek commented:

> This daring practice and its acknowledgement by a doctor signal how routine the concept of nontreatment of defective newborns has become in medical practice and how far some medical professionals have taken it.
>
> Ending a human life by overdose clearly moves the issue out of the long disputed area of passive euthanasia by withholding care into the outlawed territory of active euthanasia, or causing death.

Id. at A25, col. 1.

[19] Cohen, *Doctor Admits Hospital Let Newborns Die*, Hartford Courant, Oct. 1, 1981, at A1, col. 1. *See also* DeRenzo, Summary of Hearings on the Treatment of Newborns with Disabilities 6 (Feb. 10, 1982) (on file at U.S. Commission on Civil Rights).

[20] Duff, Decision Making in Extreme Situations 5 (Testimony prepared for presentation at hearings of the Public Health Interim Study Committee on Medical Treatment for Newborn Infants, Oct. 20, 1981).

[21] Letter from Leo F. Arria to State Sen. Regina Smith (Apr. 7, 1982) (on file at U.S. Commission on Civil Rights). Mr. Arria and his wife talked with another pediatrician and decided to authorize medical treatment. *See also* letter from Theodore and Cheryl Mekdeci to State Sen. Regina Smith (undated) (on file at the U.S. Commission on Civil Rights).

> Kimberly was placed in the Newborn Special Care Unit at Yale New Haven Hospital. [We] were approached by Dr. Duff. He wanted to know if we fully understood the future life we would be faced with. Our daughter would be a burden to us and would need constant care and may never amount to anything other than to be a vegetable, is what he had told us. There was the possibility that she would cause us much pain. We asked him if he was advis[ing] us against the surgery, asking us to take the chance of our daughter dying. He told us it was something that we should consider.[22]

The committee obtained a Yale-New Haven hospital policy that explicitly stated that among the factors to be considered in decisions to provide or withhold treatment were "the quality of life for the child and family" and "the risks of psychological burdens."[23]

The Brozek series and the legislative hearings prompted an investigation headed by Thayer Baldwin, Jr., chief of the Bureau of Health System Regulation of the Connecticut State Department of Health Services. At the conclusion of his investigation, the report of the bureau recommended against any "attempt to define or interfere with medical practice." It said "the enormous variety of personal feelings on the subject" meant that laws preventing denial of treatment "would be ignored and ineffective."[24] However, the report did make factual findings about a number of cases involving 11 hospitals around the State:

> Two. . .infants had multiple congenital anomalies involving one or more organs and body systems and including intestinal and neurological dysfunction in varying degrees. Although individual physical anomalies were treatable, with resultant varying prognoses, a physician/parent decision was made to withdraw/withhold treatment and active support, including intravenous fluids which provided nourishment. Alternative nourishment was then offered orally "as tolerated" to one of these infants. Although this infant died of "malnutrition," it is not known whether this was due to lack of adequate intake or to intestinal dysfunction. The second infant was provided no nourishment in any form and subsequently died of dehydration.
>
> . . . .
>
> [A] low birth weight, full term infant was transferred from another hospital on oxygen support. Problems noted early on included physical signs of Down's Syndrome, heart defect (probable AV canal), and probable duodenal stenosis. (The heart problem was operable, but with a high mortality rate.) The infant was prepared for duodenal surgery, however the parents chose not to perform surgery. The mother did not want the baby to suffer or to ruin the lives of their other children. . . .A physician-supported, subsequent parent decision was made to discontinue all support. A statement signed by the parents appeared in the record which stated their decision against abdominal surgery and their decision to withdraw "medical support" and their understanding of the "full meaning of this decision."
>
> All "support" was discontinued on the fourth day of life, including oral feedings (which were not feasible) and intravenous nourishment. These activities were substantiated by doctors' orders and nurses' records. At death (at 23 days old) the infant showed a substantial weight loss from birth.
>
> [A] severely premature infant required suctioning for resuscitation. . . .A genetic consult confirmed the probability of Down's. A surgical consult revealed probable duodenal atresia. There were several instances of bradycardia (slow heart rate) beginning on the first day of life. On the third day of life, the parents made a decision to "let nature take its course" and opted for "non-active intervention". . . .[R]ecords indicated that the IV line (which included nourishment), antibiotics and other support were withdrawn on the third day. The infant died on the fourth day, following increased episodes of bradycardia.
>
> . . . .
>
> [F]our infants had multiple congenital anomalies and physiological and medical problems including varying degrees of cardiorespiratory and/or neurological deficiencies. (An infant with Down's Syndrome was included in this group.) Physician/parent decisions were made to withhold or withdraw artificial means of respiration from these infants apparently based on prognoses of poor quality lives from complications requiring continuing extensive support.
>
> . . . .
>
> . . .Notes such as "Plan is to not ventilate the infant. . . .The parents accept this plan," "little chance of even a remotely normal life," "multiple surgery and maximal family support and medical care will be required

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[22] Letter from Theodore and Cheryl Mekdeci to State Sen. Regina Smith (undated) (on file at the U.S. Commission on Civil Rights). The Mekdecis wrote:

> This time [after birth] is a very trying time for the parents and being persuaded in the direction of ending the newborn child[']s life is something that might be regreted [sic] later if parents were to decide this way without feeling that there are other alternatives. . . .
>
> Kimberly today is mainstreamed into a regular classroom at school. She is socially and emotionally well adjusted and is a beautifully bright individual. She also shows much love.

[23] Guidelines for Deciding Care of Critically Ill or Dying Patients[:] A Summary of the Yale-New Haven Hospital Policy 5 (undated) (on file at the U.S. Commission on Civil Rights).

[24] Baldwin, Infant Death[:] Life and Death in Newborn Special Care Units 11 (1982) (on file at U.S. Commission on Civil Rights). See chap. 10 and text accompanying notes 38-40.

> to achieve a reasonable life". . .were observed in the medical records. . . .
>
> Articles in the Hartford Courant which precipitated this investigation by the Department of Health Services referred to cases in which infants were starved or overdosed at home. In three of the eighteen cases reviewed, the infant died at home. Our review of hospital records did not provide enough information to either prove or rule out any malfeasance after discharge from the hospital. However, there appears to be a high possibility that active euthanasia was involved in at least one of these cases.
>
> . . . .
>
> . . .From our review, it would appear that in every hospital in which we reviewed records, selective life/death decisions, involving withdrawal or withholding of treatment, were being made by physicians and parents on a case by case basis.
>
> . . .Some records at one institution included signed statements by parents that it was their decision to withdraw treatment even though death would necessarily follow.[25]

On June 17, 1982, State Senator Smith filed a formal complaint with the U.S. Department of Justice, to which she attached the Brozek articles, the Baldwin report, and information from testimony given at the hearings before her committee (including the two parental letters concerning Dr. Duff quoted earlier).[26] She requested an investigation "to determine whether or not Section 504 of the Rehabilitation Act or any other federal criminal or civil statute is being ignored and violated."[27] The Justice Department did not itself initiate an investigation and did not refer the complaint to the HHS Office for Civil Rights until October 1982.[28] It was not until February 10, 1983, that any response was sent to Senator Smith on her complaint. On that date Caroline Chang, Region I Director of the Office for Civil Rights, wrote her to inform her that on February 1, 1983 (3 months after the complaint had been referred to OCR by the Justice Department), her complaint had been referred to the Region I office for investigation. The Chang letter continued:

> You have provided OCR with complete information sufficient to initiate our processing of your complaint. OCR has jurisdiction over the subject matter of the complaint pursuant to Section 504 of the Rehabilitation Act of 1973. . . .
>
> We have determined that Yale-New Haven Hospital is a recipient of Federal financial assistance from the Department of Health and Human Services. . .
>
> In approximately ninety days, OCR will complete its investigation to determine if there has been a violation of Section 504 and its regulation. If no violation is identified, OCR will inform you and Yale-New Haven hospital in writing. If there is a determination that a violation has occurred, Yale-New Haven Hospital will be notified and requested to take corrective action within the next ninety days.[29]

However, Peter Chan of the Region I office telephoned Senator Smith some months later to tell her that the investigation would take longer than expected. Finally, approximately a year later, he informed her that the investigation had been concluded at the regional level.[30] The investigative findings were cleared at the regional level on March 2, 1984, and the national office cleared a letter of finding on May 18, 1984.[31] In the meantime, however, enforcement was suspended in March 1984 as a consequence of the suit challenging the final rules.[32] As a result, the letter of finding was never issued.[33]

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[25] *Id.* at 14–17. In another case involving a child with "perinatal and neonatal asphyxia resulting in serious brain damage and related complications," who was "able to breathe room air and to be fed by mouth," a "parent/physician decision had been made. . .to discontinue tube feedings and feed only by mouth on demand with the expectation that this course would result in death." The infant was "discharged home. . .and subsequently died at home of cardiorespiratory arrest." *Id.* at 16.

[26] Letter from State Sen. Regina Smith to William Bradford Reynolds, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, and Arthur Peabody, Special Litigation Section, U.S. Department of Justice (June 17, 1982) (on file at U.S. Commission on Civil Rights).

[27] *Id.* at 1.

[28] Memorandum from Betty Lou Dotson, Director, Office for Civil Rights, U.S. Department of Health and Human Services, to Thomas Donnelly, Acting Secretary, U.S. Department of Health and Human Services 1 (Mar. 1, 1983). According to Ms. Dotson, "OCR had already initiated a compliance review of the Yale-New Haven Hospital in August 1982, which covered the same issues involved in the Regina Smith complaint." *Id.* According to Yale-New Haven Hospital, it received a letter announcing a civil rights compliance review on July 27, 1982, and Federal investigators arrived on Sept. 14, 1982.

> During the fall of 1982, HHS personnel reviewed over one hundred charts of deaths between January and June, 1981, and March through August, of 1982. They subsequently reviewed 110 charts of babies with specified conditions admitted between October 1979 and December 1982. They also conducted extensive reviews with Hospital physicians, nurses, social workers, administrators and others. . . .In March, 1983, OCR Investigator Peter Chan returned to the Hospital for additional interviews with physicians. On July 21, 1983, Investigator Chan again met with representatives of the Hospital requesting additional information.

Letter from John E. Fenn, Chief of Staff, Yale-New Haven Hospital to William J. Howard, General Counsel, U.S. Commission on Civil Rights 1–2 (Oct. 6, 1988) (printed in app. D of this report).

[29] Letter from Caroline Chang, Region I Director, Office for Civil Rights, U.S. Department of Health and Human Services, to State Sen. Regina Smith (Feb. 10, 1983) (on file at U.S. Commission on Civil Rights).

[30] Telephone interview with State Sen. Regina Smith (Sept. 16, 1988).

In short, in a matter that by its nature was a matter of life and death, it took nearly 2 years from the time the complaint was filed to bring an investigation to conclusion, at least 10 months of which was used after the investigators' medical chart review and interviews of hospital personnel had already occurred. By the time HHS was finally ready to act, it was too late.

This pattern was to continue. In October 1983, an article entitled "Early Management and Decision Making for the Treatment of Myelomeningocele" was published in *Pediatrics*,[34] the journal of the American Academy of Pediatrics. The authors were Richard H. Gross, MD, Alan Cox, MD, Ruth Tatyrek, MSW, Michael Pollay, MD, and William A. Barnes, MD. They were from the departments of Orthopaedic Surgery, Pediatrics, Neurosurgery, and Urology of the University of Oklahoma Health Sciences Center, and Department of Social Service, Oklahoma Children's Hospital, Oklahoma City.[35]

The article described a selective treatment program carried out at Oklahoma Children's Hospital. The article tracked the "treatment" regimen for 69 infants born with spina bifida between July 1, 1977, and June 30, 1982.[36] According to the article, a hospital team assessed each infant within 48 hours of birth. For those infants born with high lesions who were suspected of having hydrocephalus or other anomalies, a meeting was convened to decide upon a treatment recommendation to the family. The recommendation could be for "vigorous" treatment or for "supportive care."[37] "Supportive care" meant that lifesaving surgery to close the lesion would not be performed and "active treatment" would not be given "for infection and other acute illnesses."[38] In addition, the criteria used by the team included an assessment of "contribution from home and family" so that those families who had greater resources might receive a recommendation for treatment and those families with fewer resources would be more likely to receive a recommendation against it, even though the severity of the disability might be the same in both cases.[39]

Of the 69 infants in the experiment, 36, or 52 percent, were recommended for treatment. Thirty-three, or 48 percent, were recommended for "supportive care." Of those recommended for treatment, all survived with the exception of one who died as a result of a car accident. Twenty-eight of the families receiving the recommendation for nontreatment (supportive care) accepted the recommendation. The families of five children demanded treatment, and of those five children, three, according to the authors, "are alive and well."[40] The majority of infants for whom no treatment was planned were sent to a facility called the Children's Shelter.[41] At the end of the experiment, 24 families had finally agreed to the nontreatment regimen, and all 24 children died. The experiment was called a success by the authors: "[T]his approach seems to us the best alternative available at this time."[42]

The *Pediatrics* article came to the attention of Carlton Sherwood, one of only two investigative reporters to have won both the Pulitzer and the Peabody awards for investigative reporting. He was then working for Cable News Network and took a television crew with him to Oklahoma. Initially, he was denied interviews by both the hospital and the Children's Shelter, a facility to which, according to the article, children being provided only "supportive care" were frequently sent. One snowy Sunday, however, a nurse named George McCormack decided not only to allow the reporter and camera crew inside the shelter, but also to tell the story of his unsuccessful attempts to obtain lifesaving surgery for a baby born with spina bifida who had not been treated.[43]

Sherwood's camera captured the picture of Carlton Johnson, a black baby born with spina bifida to an unmarried mother receiving welfare.[44] A large sac was visible on Carlton Johnson's back, according to McCormack the result of the refusal of Oklahoma Memorial Hospital-associated physicians to treat him. McCormick told the reporter that he had requested an operation for Carlton Johnson on more than one occasion.[45]

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[31] Telephone interview with Patricia Mackey, Office for Civil Rights, U.S. Department of Health and Human Services (Sept. 20, 1988).

[32] Telephone interview with Peter Chan, Region I Office, Office of Civil Rights, U.S. Department of Health and Human Services (Sept. 19, 1988).

[33] Telephone interview with Patricia Mackey, Office for Civil Rights, U.S. Department of Health and Human Services (Sept. 20, 1988).

[34] Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983).

[35] *Id.* at 450.

[36] *Id.* at 452.

[37] *Id.*

[38] *Id.* at 452, 453.

[39] *Id.* at 456.

[40] *Id.* at 451.

[41] *Id.* at 452.

[42] *Id.* at 457.

[43] Interviews with Carlton Sherwood (February 1984).

Sherwood's discoveries and interview with McCormack were aired in February 1984, as part of a three-part series on Cable News Network which provided graphic evidence that the Oklahoma Children's Hospital not only had conducted the selective treatment experiment but also was apparently still refusing to provide necessary medical treatment to children born with surgically correctable problems, especially if the child came from a poor family.

Of particular importance for the future legal status of calls for Federal investigation of the selection process was an interview with Carlton Johnson's mother. Sharon Johnson stated that the doctors had told her that her child could not live. She had no idea that with an operation her son would be able to move into a family home and live as normal a life as his disability would allow.[46] This evidence suggested that the physicians were not simply deferring to parental decisions, but rather securing parental consent to nontreatment by providing unwarrantably pessimistic prognoses. It raised the question of whether parents were in fact giving legally effective informed consent.

Attention within the disability rights movement was drawn to the *Pediatrics* article soon after it was published. Michael Lottman, a disability rights attorney and former Justice Department official, drafted a letter alleging that the Oklahoma procedures entailed various constitutional and statutory violations.[47] His draft was brought to Martin Gerry, former director of the Office for Civil Rights in the Department of Health, Education, and Welfare.[48] Gerry agreed with the basic findings in the Lottman draft and circulated a revised letter of complaint to various disability rights groups. The Association for Persons with Severe Handicaps, the Association for Retarded Citizens/United States, the National Down Syndrome Congress, the Spina Bifida Association of America, Martin Gerry, and Nat Hentoff, a civil libertarian columnist for the New York City weekly *The Village Voice,* joined in the formal complaint.[49]

On February 24, 1984, the written complaint was submitted to both Attorney General William French Smith and Margaret Heckler, Secretary of the Department of Health and Human Services.[50] The complaint alleged violations of three Federal statutes and the HHS regulations involving human experimentation.[51] It emphasized the urgency of government action in response to the complaint. "It is imperative that the Federal Government act decisively to put an end to these multiple and longstanding illegalities, and that intervention be effected immediately before more lives are lost. If existing administrative procedures. . .cannot move quickly enough in this desperate situation, then the government must go to court to put an end to these deaths pending a final administrative or judicial determination."[52]

The Department of Health and Human Services is required to investigate complaints "promptly."[53] Despite the life-threatening urgency of the allegations in the complaint, 96 days passed before the

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[44] Interviews with Carlton Sherwood (February 1984).

[45] Cable News Network Transcript, *Who Lives, Who Dies?* 3 (Feb. 21, 22, & 24, 1984) (on file at U.S. Commission on Civil Rights).

[46] *Id.*

[47] Telephone interview with Michael Lottman (Aug. 24, 1988).

[48] The Department of Health, Education, and Welfare was subsequently divided into HHS and the Department of Education. HHS now has responsibility for these issues.

[49] Interview with Martin Gerry (Sept. 13, 1988).

[50] Letter to William French Smith, Attorney General, U.S. Department of Justice, and Margaret Heckler, Secretary, U.S. Department of Health and Human Services (Feb. 24, 1984) (on file at U.S. Commission on Civil Rights).

[51] The alleged violations were of section 504 of the Rehabilitation Act, 29 U.S.C.A. §794 (1985); of the medicaid requirements that services not be denied to eligible recipients without a fair hearing, 42 U.S.C.A. §1396a(a)(3) (West Supp. 1988); that medical assistance to eligible recipients be of the same amount, duration, and scope as that provided to others, 42 U.S.C.A. §1396a(a)(10)(B) (West Supp. 1988); and that care and services be provided in a manner consistent with the best interests of the recipient, 42 U.S.C.A. §1396a(a)(19) (West Supp. 1988); of regulations governing experimentation on human subjects, forbidding such experimentation without informed consent, 45 C.F.R. §§46.116, 46.406 & 46.408 (1987); and of the Federal criminal code, 18 U.S.C.A. §§241 & 242 (1969). Letter to William French Smith, Attorney General, U.S. Department of Justice, and Margaret Heckler, Secretary, U.S. Department of Health and Human Services 5, 6 (Feb. 24, 1984) (on file at U.S. Commission on Civil Rights).

[52] The letter invoked United States v. Frazer, 297 F. Supp. 319 (M.D. Ala. 1968) as precedent for such a suit. Letter to William French Smith, Attorney General, U.S. Department of Justice, and Margaret Heckler, Secretary, U.S. Department of Health and Human Services 6 (Feb. 24, 1984) (on file at U.S. Commission on Civil Rights).

[53] 45 C.F.R. §§84.61 & 80.7(c) (1987).

Office for Civil Rights (OCR) took measurable action on the complaint. On May 30, 1984, a meeting was convened in Washington, D.C., attended by Betty Lou Dotson, OCR director; Surgeon General C. Everett Koop; Kent Smith, executive director of the Spina Bifida Association of America; and two private physicians who had been critical of the practices reported at Oklahoma Children's Hospital, Dr. David McClone of Chicago Children's Hospital and Dr. John Freeman of Johns Hopkins Hospital in Baltimore. Dr. Freeman later wrote that to "defus[e] the adversarial approach" and "prevent the necessity for and the problems inherent in litigation," it was the "consensus of the meeting. . .to use a more indirect approach to the University of Oklahoma through Dr. Koop and the Spina Bifida Association to see what current practices are being utilized by the University of Oklahoma in their determinations of who should be treated."[84] Physicians at the hospital refused to give the Surgeon General assurances that the practices had ceased.[85]

Disturbed by the reports of this meeting and wanting to make clear that the presence of a representative of one of the complainant groups at the meeting could not be interpreted as adequate justification for a failure to undertake a formal investigation and appropriate legal action,[86] Martin Gerry on June 4, 1984, wrote identical letters to the Attorney General and the Secretary of Health and Human Services "to advise. . .formally that I represent each of the organizations and individuals listed on the signature page of the February 24, 1984, letter in connection with matters raised in the Complaint." The letter emphasized that the February letter "represents a true and complete complaint" with regard to which 45 C.F.R. §80.7 required "that the Department of Health and Human Services initiate a prompt investigation 'whenever a compliance review, report, *complaint, or any other information* indicates a possible failure to comply' with the law," and to ask the Department to "designat[e] a liaison. . .for us to contact in order to avoid any future confusion."[87]

On July 2, 1984, Betty Lou Dotson, Director of the Office for Civil Rights in the Department of Health and Human Services, responded to the June 4 letter to Secretary Heckler. She stated:

> When this matter came to our attention in February, we initiated efforts to develop a comprehensive and legally viable investigative plan. These efforts included a May 30, 1984, meeting with the Surgeon General, two nationally recognized medical experts on spina bifida, the Executive Director of the Spina Bifida Association of America (a cosigner of your earlier letter on this subject), and others. That meeting produced a consensus on the initial steps to be taken to most effectively deal with this serious matter. Also during the course of these preliminary efforts, we received information, seemingly reliable but not independently verified, that the treatment procedures followed during the 1977–82 time period are no longer in effect at the University of Oklahoma Health Sciences Center.[88]

The letter also stated that after the March 12, 1984, filing of a suit to enjoin the section 504 "Baby Doe" regulations, HHS, in order to avert a preliminary injunction, had agreed "to delay, until resolution of the litigation, direct investigation of complaints not involving live infants at risk." It pointed out that on June 11 the district court had issued an injunction barring HHS from investigating treatment decisions concerning newborn infants under section 504.

The letter recognized that the complainants "also asked that this issue be reviewed from the context of HHS regulations regarding the Medicaid program and human experimentation." It justified not having considered these issues because "HHS has concentrated its efforts to assure appropriate treatment for handicapped infants on enforcement of section 504, the approach we believed to have the strongest legal basis." In light of the court order precluding use of this basis, Ms. Dotson wrote, "I have forwarded your complaint to the appropriate HHS offices for review pursuant to these other authorities. . . .You can be sure all appropriate actions within our legal authority will be taken."[59]

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[84] Letter from John Freeman to Betty Lou Dotson, Director, Office for Civil Rights, U.S. Department of Health and Human Services, and C. Everett Koop, Surgeon General of the United States (May 30, 1984) (on file at U.S. Commission on Civil Rights).

[85] Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment,"* 1 Issues in L. & Med. 15, 56 (1985), citing telephone interview with C. Everett Koop, Surgeon General of the United States (Nov. 16, 1984).

[86] Interview with Martin Gerry (Sept. 13, 1988).

[87] Letter from Martin Gerry to William French Smith, Attorney General, U.S. Department of Justice (June 4, 1984) (emphasis in original); letter from Martin Gerry to Margaret Heckler, Secretary, U.S. Department of Health and Human Services (June 4, 1984) (emphasis in original) (on file at U.S. Commission on Civil Rights).

[88] Letter from Betty Lou Dotson, Director, Office for Civil Rights, U.S. Department of Health and Human Services, to Martin Gerry (July 2, 1984) (date of June 29, 1984, also appears on letter) (on file at U.S. Commission on Civil Rights).

On July 3, 1984, William Bradford Reynolds, Assistant Attorney General of the Civil Rights Division of the Justice Department, responded to Mr. Gerry's June 4 letter to Attorney General Smith. The Justice Department letter stated that "(u)nder federal regulations, this Department's role in enforcing section 504 does not ordinarily commence until the Department of Health and Human Services or other authorized agency has referred a matter of violation of section 504 to us for appropriate action." Presumably referring to the May 30 meeting, Reynolds said: "In response to my recent inquiry on the status of such an investigation, the Department of Health and Human Services advised that it was in the process of convening a group of experts to develop an investigative plan and that the activities of the Center were in the interim being appropriately monitored." However, he wrote, in light of the district court injunction, "recent judicial action prevents further HHS action in this area at this time."

> You also suggest that we consider criminal prosecutions under 18 U.S.C. [§§]241 and 242. Those statutes create no independent rights, but depend on proof of violation of existing federal rights. As of now, the court decisions on the treatment of handicapped infants under Section 504 negate any federal right in that area. Even if we prevail in our position that Section 504 protects newborn infants against discrimination based on handicap, we believe that addressing the issue under Section 504 would be more satisfactory than criminal proceedings.[60]

On July 13, 1984, Martin Gerry again wrote Secretary Heckler on behalf of the complainants, charging that "at least twelve additional disabled infants [had] been unlawfully denied treatment by the same facilities" in the preceding 3 months. He challenged the conclusion that action by the Department under section 504 was precluded, maintaining that the New York court's injunction need not be interpreted to preclude investigation of a complaint related to Oklahoma.[61] Secretary Heckler replied on October 11, 1984, reaffirming the conclusion of the HHS and Justice Departments that the New York court's injunction had nationwide effect and precluded further HHS action.[62]

In October 1985, the American Civil Liberties Union and the National Center for the Medically Dependent and Disabled (a Legal Services Corporation-funded national support center) filed suit against a number of physicians at Oklahoma Children's Hospital. The suit was filed on behalf of Sharon Johnson (Carlton Johnson's mother), Carlton Johnson himself, the parents of another child with disabilities who had died after allegedly being denied lifesaving treatment at Oklahoma Children's Hospital, the Spina Bifida Association of America, and the Association for Persons with Severe Handicaps.[63]

On February 12, 1987, several Members of Congress wrote HHS Secretary Otis Bowen to solicit involvement of the Department in the case, which would include an HHS request for Justice Department intervention.[64] Central to the letter was an argument based on the Supreme Court's decision in *Bowen v. American Hospital Association*.[65] *Bowen* had narrowed the injunction that, as entered by the lower courts, had forbidden HHS to investigate any cases involving denial of treatment to newborn children under the aegis of section 504. *Bowen* prohibited only investigation of such cases where there had been parental consent to the treatment withholding. In the *Johnson* case, the plaintiffs alleged that decisions to deny treatment were made by hospital personnel without legally valid parental consent. However, HHS never agreed to be involved or to request the intervention of the Justice Department.

The pattern is clear. The disability rights organizations and Members of Congress ultimately fared no better with regard to Oklahoma Children's Hospital than did the Public Health Committee of the Connecticut State Legislature with regard to

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[59] *Id.* As of September 1988, HHS had not informed the complainants of any investigations conducted, action taken, or determinations made with regard to the Oklahoma complaint under these other authorities. Interview with Martin Gerry (Sept. 13, 1988).

[60] Letter from William Bradford Reynolds, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, to Martin Gerry (July 3, 1984) (on file at U.S. Commission on Civil Rights).

[61] Letter from Martin Gerry to Margaret Heckler, Secretary, U.S. Department of Health and Human Services (July 13, 1984) (on file at U.S. Commission on Civil Rights).

[62] Letter from Margaret Heckler, Secretary, U.S. Department of Health and Human Services, to Martin Gerry (Oct. 11, 1984) (on file at U.S. Commission on Civil Rights).

[63] Johnson v. Sullivan, No. CIV-85-2434A (W.D. Okla. filed Oct. 3, 1985).

[64] Letter from U.S. Reps. Beau Boulter, Thomas Bliley, Bob Dornan, Chris Smith, Jack Kemp, Harold Volkmer, and Henry Hyde to Otis Bowen, Secretary, U.S. Department of Health and Human Services (Feb. 12, 1987).

[65] 476 U.S. 610 (1986). For further discussion of this case, see chap. 6 and text accompanying notes 108-135.

Yale-New Haven Hospital. No legal action was taken to stop the well-documented denials of treatment.

In both instances, official complaints were documented by credible and detailed information strongly suggesting violations of section 504. In both instances, the complaints detailed an ongoing pattern or practice that suggested that lives continued to be at risk. In both instances, prompt action would have allowed investigations and compliance action to be taken before there was any judicial bar.[66] It took the Justice Department more than 3 months to refer the Connecticut complaint to OCR; it took OCR more than 3 months to refer it to its regional office for investigation; and despite a pledge to complete the investigation in approximately 3 months, it took 15 months—by which time it was too late. It took OCR more than 3 months to take any significant action on the Oklahoma complaint—and when it did, the action was to substitute informal inquiries for the legally required investigation. In short, confronted with substantial evidence of significant and ongoing denial of lifesaving treatment to children with disabilities, evidence that suggested an ongoing threat to lives in both States, the responsible Federal agency failed to act with the vigor and dispatch incumbent on it in light of the circumstances, its legal responsibilities, and its publicly stated position.

The Child Abuse Amendments of 1984

The second major Federal role in enforcing the rights of children with disabilities to be free from medical discrimination came with the effective date of the Child Abuse Amendments of 1984. Beginning on October 9, 1985, and continuing through the present, the National Center for Child Abuse and Neglect in the Office of Human Development Services at HHS has had the responsibility for enforcing the requirements these grants impose upon the States.

This report has already detailed the failure of a number of State Child Protective Services agency standards and procedures to meet the prerequisites for Federal funding embodied in the Child Abuse Amendments and their implementing regulations. Nevertheless, these States have all been certified by HHS for receipt of Federal funds under the Child Abuse Prevention and Treatment Act, without being advised that they are out of compliance or being given any deadline to bring their standards and procedures into compliance.[67] The Commission considers this a significant failing on the part of HHS.

In 1987 the Office of Analysis and Inspections of the HHS Office of Inspector General did two studies in response to the requirement of the Child Abuse Amendments that "[n]ot later than October 1, 1987, the Secretary shall submit to the appropriate Committees of the Congress a detailed report on the implementation and the effects of the provisions of this part and the amendments made by it."[68] One study focused on State Child Protection Services' implementation of the Child Abuse Amendments,[69] while the other dealt with hospital review committees.[70] Certain portions of those reports evince a disturbing failure on the part of the Inspector General personnel involved in writing them either fully to understand the requirements of the Child Abuse Amendments or to make the appropriate inquiries to determine whether they are being carried out.

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[66] Courts are often influenced by the circumstances of precedent-setting cases. Both the *Bowen* Supreme Court decision and the Second Circuit decision in *University Hospital* were issued by a closely divided court. Given the compelling and sympathetic nature of the facts, if litigation had been initiated in either the Connecticut or the Oklahoma cases, it is at least possible that the decisions ultimately rendered concerning the applicability of 504 rendered by the courts might have been different.

[67] *See* chap. 10.

[68] 42 U.S.C.A. §5103 note (West Supp. 1988). In comments submitted on a draft of this report, reprinted in app. E, the HHS Inspector General stated that it was "incorrect" to characterize the two studies as made in response to the requirement of the Child Abuse Amendments. Letter from Richard Kusserow, Inspector General, to William J. Howard, General Counsel, U.S. Commission on Civil Rights 1 (Oct. 12, 1988). However, on June 8, 1988, HHS Secretary Otis Bowen submitted them to Congress with a document entitled "Report to the Congress: Implementation of the Child Abuse Amendments of 1984 Relating to the Protection and Care of Disabled Infants With Life-Threatening Conditions" (on file at U.S. Commission on Civil Rights). That document described its purpose as "to provide to the Congress, as required by Section 126 of Public Law 98-457 (the Child Abuse Amendments of 1984), a detailed report on the implementation and the effects of the provisions of this legislation for disabled infants with life-threatening conditions." *Id.* at i. It stated: "[T]he Department. . .requested an inspection by the Office of Inspector General (OIG) to (a) determine state compliance with these new requirements, and (b) review hospitals' use of the Model Guidelines for Infant Care Review Committees. This study, conducted in FY 1987, found that the States and the hospitals are complying with the legislation." *Id.* at ii.

[69] Office of Inspector General, Department of Health and Human Services, Survey of State Baby Doe Programs (1987) [hereinafter State Agencies OIG Report].

[70] Office of Inspector General, Department of Health and Human Services, Infant Care Review Committees Under the Baby Doe Program (1987) [hereinafter Committees OIG Report].

In the report on infant care review committees, for example, the Office of the Inspector General noted that of the "between 20 and 36 potential Baby Doe cases since the Federal regulations went into effect in October 1985" considered by the 10 committees whose activities were monitored, only 3 were reported to state CPS agencies.[71] The Office of Inspector General did not review the facts in these unreported cases to determine whether or not they met the standards established in the Child Abuse Amendments. It is hard to see how, without doing this, the Department could accomplish its task of ascertaining whether the committees are fulfilling what HHS has described as "the role of the ICRC [infant care review committee] to review the case. . .and recommend that the hospital seek CPS agency involvement when necessary to assure protection for the infant and compliance with applicable legal standards."[72]

It is equally disturbing that, apparently as a typical exemplar of such committees generally, the OIG report provides a detailed description of the "interlocking Infant Bioethical Review Committees. . .in four affiliated hospitals which make up the Albert Einstein College of Medicine and the Montefiore Medical Center in Bronx, New York," including an account of the "set of principles which serve as the basis for making decisions involving critically ill infants," without pointing out that those principles differ from the treatment standards required by the Child Abuse Amendments.[73]

The OIG report does make clear that, as discussed in some detail above, most of the committees surveyed review only cases in which there is disagreement among health care personnel or between them and family members, and do not report to CPS agencies if the disagreement can be resolved—regardless, for all the OIG report shows, of whether the agreed resolution abides by or violates the treatment principles embodied in the Child Abuse Amendments.[74] In light of these significant indications of lack of compliance,[75] it is disconcerting that the official reaction of the then Acting Assistant Secretary for Human Development Services was that, "Overall, we are encouraged by the findings, observations, and data contained in these reports. . . .The findings and data reported do not raise serious questions or issues for our attention."[76]

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[71] *Id.* at 9. See chap. 11, text accompanying notes 73-77, for a discussion of the provisions of the Child Abuse Prevention and Treatment Act that require all "suspected" cases of withholding of medically indicated treatment be reported, not merely those in which a hospital committee finally decides that such has in fact occurred or is about to occur. The Inspector General's report fails to comment on this apparently widespread noncompliance, and HHS has neglected to take any action to inform States that toleration of such illegal failure to report does not meet their responsibilities under the relevant law.

[72] Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14880-81 (1985).

[73] Committees OIG Report, *supra,* note 70, at 11-12. The Committees OIG Report describes the principles as recognizing that "[w]ithholding or withdrawing treatment may be considered when it is deemed futile and would merely prolong the dying process or when the medical treatment imposes a burden which lacks compensating benefits for the Infant. If such a decision is made, the infant and the family are cared for in a supportive and dignified manner." *Id.* at 11. *Cf.* 45 C.F.R. §1340.15(b)(2) (1987). In his letter commenting upon a draft of this report, the Inspector General described this passage as "misleading" because "[t]he purpose of this portion of the report was simply to serve as a reference to other hospitals considering the establishment of similar committees." Letter from Richard Kusserow, Inspector General, to William J. Howard, General Counsel, U.S. Commission on Civil Rights 2 (Oct. 12, 1988). But that is precisely what the Commission criticizes: a government agency suggesting that a committee employing principles out of compliance with the law is a fit reference for other hospitals that might establish such committees.

[74] See chap. 11.

[75] Facts indicating other instances of incomplete compliance are included in the report on State agencies. 45 C.F.R. §1340.15(c)(3) (1986) requires:

> The programs and/or procedures must specify that the child protective services system will promptly contact each health care facility to obtain the name, title, and telephone number of the individual(s) designated by such facility for the purpose of the coordination, consultation, and notification activities . . ., and will at least annually recontact each health care facility to obtain any changes in the designations.

The Agencies OIG report discloses that as of March 1987, five States admitted that more than one-third of their hospitals with neonatal intensive care units or obstetrical units had not designated such liaisons, 13 States admitted that some number of such hospitals (less than one-third) had not done so, and 3 States admitted that they did not know how many had done so. State agencies OIG Report at 4, *supra,* note 69. Furthermore, only 28 States stated that they updated their lists of liaisons annually, as required; 5 stated they update "periodically or as needed," while the others apparently failed to reply. (The Agencies OIG Report leaves unclear whether some of the 28 States did not receive Federal funds, and thus were not required to comply with the Child Abuse Amendments.) *Id.*

[76] Memorandum from Phillip N. Hawkes, Acting Assistant Secretary for Human Development Service, HHS, to Richard P. Kusserow, Inspector General, HHS (Sept. 11, 1987) *reprinted in* Committees OIG Report, *supra,* note 70 at app. E at 1-2. The Acting Assistant Secretary did not express concern that 22 percent of the State agencies "responded that, because of the medical and ethical issues involved, CPS responsibility for Baby Doe cases is not appropriate. We will consider what appropriate action HDS [Office of Human Development Services] might take

However, after reviewing a draft of relevant portions of this report, Assistant Secretary Sydney Olson commented:

> We are extremely concerned about your findings which indicate that a number of State Child Protective Service (CPS) agencies may fail to meet the requirements for federal funding as provided for in 45 C.F.R. 1340.15, and your statement that the Department of Health and Human Services has incorrectly certified them as eligible. The issues you raise are indeed serious.[77]

The letter stated that "[b]ecause of the information compiled in the [Civil Rights Commission draft] report," the HHS Office of Human Development Services will convene a staff work group "to review our current policies and instructions to determine if there are ways in which we can improve the administration of the Federal program and the use of Federal funds to accomplish its purposes" and "will review the eligibility of each State cited in your report, paying special attention to those areas of concern that you have identified."[78]

Conclusion

The Commission is dismayed at the extremely poor performance of the Department of Health and Human Services in fulfilling its responsibilities to protect children with disabilities from medical discrimination, first under section 504 of the Rehabilitation Act in the time period before its use was enjoined, and currently under the Child Abuse Amendments of 1984. That performance requires substantial improvement. Although the Commission is encouraged by steps the Office of Human Development Services now states it will take in response to this report, it is too soon to determine whether they will result in the very significant increase in scrutiny of the performance of recipient State child protective services agencies that is essential if the Department is effectively to fulfill its responsibilities under the law.

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to further clarify and reinforce CPS agency responsibilities." *Id.* at app. E at 2.

[77] Letter from Sydney Olson, Assistant Secretary, Office of Human Development Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights 1 (Oct. 31, 1988) (reprinted in app. E of this report).

[78] *Id.* at 2.

Chapter 13

The Protection and Advocacy System: A Resource for Enforcement

In 1975 Congress established structures called Protection and Advocacy Systems (P&A), originally attuned specifically to the need to ensure vigorous advocacy of the rights of persons with developmental disabilities.[1] The Developmentally Disabled Assistance and Bill of Rights Act required that each State or similar jurisdiction receiving Federal funding for persons with developmental disabilities establish an independent system with "authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of [persons with developmental disabilities]."[2]

In 1984, in substantially expanding funding for the P&A systems, Congress recognized both their importance and their impressive track record. The Senate Committee on Labor and Human Resources Report noted:

> The Committee views State Protection and Advocacy Systems (P&A's) to be of critical importance in an expanding effort by the Congress to assure disabled persons. . .protection of their rights under law. . . .[T]he P&A's provide an invaluable local and thus available resource to developmentally disabled people which is independent, yet knowledgeable of service providers. The Committee notes favorably the testimony provided by Dr. Jean Elder, Commissioner of the Administration on Developmental Disabilities that "[i]n FY 1982, 41 State P&A systems served more tha[n] 41,000 persons."[3]

In 1986, "[b]ecause of the past accomplishments of the Developmentally Disabled Protection and Advocacy System [DD P&A]," Congress chose "to build on the experience of the existing DD P&A System in investigating and resolving situations involving abuse and neglect"[4] of persons with mental illness by adding responsibility for advocacy for this population to the P&As.[5] In fiscal year 1987, the P&A systems were appropriated $15.5 million for advocacy on behalf of persons with developmental disabilities and $10.5 million for advocacy on behalf of persons with mental illness.[6] With these funds, the P&As provided advocacy for 70,501 persons with developmental disabilities (of whom 2,823 were represented in the context of medical and/or mental health services) and for 9,758 persons with mental illness (of whom 1,254 were represented in the context of alleged neglect in the provision of medical/mental health treatment).[7] These figures do not include the more than 160,000 individuals represented in class action suits in which the number is known, or those represented in class action suits in which the number is not known.[8]

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[1] The law currently defines "developmental disability" to mean:
a severe, chronic disability of a person which—
(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(B) is manifested before the person attains age twenty-two;
(C) is likely to continue indefinitely;
(D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and
(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.
42 U.S.C.A. §6001(5) (West Supp. 1988).

[2] Pub. L. No. 94–103, sec. 203, §113, 89 Stat. 486, 504 (1975) (current version at 42 U.S.C.A. §6042 (West Supp. 1988)).

[3] S. Rep. No. 493, 98th Cong., 2d Sess. 28, *reprinted in* 1984 U.S. Code Cong. & Admin. News 4334, 4361.

[4] S. Rep. No. 109, 99th Cong., 1st Sess. 3, 8, *reprinted in* 1986 U.S. Code Cong. & Admin. News 1361, 1363, 1368.

[5] Protection and Advocacy for Mentally Ill Individuals Act of 1986, Pub. L. No. 99-319, 100 Stat. 478 (codified at 42 U.S.C.A. §§10801 to 10851 (West Supp. 1988)).

[6] National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 2, 3 (1988).

[7] *Id.* at 5, 7, 13, 15.

> P&A staff consist of attorneys, social workers and other advocates who are capable of providing a full range of advocacy services including the ability to pursue legal, administrative and other appropriate remedies to protect the rights of clients. . . .
>
> P&A activities include: (1) investigating, negotiating or mediating solutions to problems expressed by persons with developmental disabilities, persons with mental illness or clients of DVRs [departments of vocational rehabilitation], their families or agency representatives; (2) providing technical assistance to attorneys, governmental agencies and service providers; (3) providing legal counsel and litigation services to persons in this population and groups who are unable to attain adequate or appropriate legal services in their communities; and (4) training advocates, consumers, volunteers, professionals, and other parties.[9]

The United States Commission on Civil Rights thinks that the P&A system affords an experienced and appropriate resource to remedy discriminatory denial of medical treatment, food, and fluids to people with disabilities. It is clear that P&As currently have a general jurisdiction that encompasses such instances.[10] Indeed, P&As have handled some such cases in the past. In 1983 the Idaho agency, Coalition of Advocates for the Disabled, was involved in the highly publicized "Baby Ashley" case, defending the right of a child born with hydranencephaly to receive treatment.[11] In 1986 the Minnesota agency, the Minnesota Mental Health Law Project, represented hospital residents with treatment-related concerns.[12] In 1987 the Mississippi agency, Mississippi P&A System for DD, Inc., was involved in a case concerning refusal by a medicare-medicaid recipient State hospital to provide life-preserving dialysis treatment to an individual dually diagnosed with developmental disabilities and mental illness.[13] But the P&A system has not been called upon for the bulk of enforcement in this area. In dealing with denial of treatment to children with disabilities in 1984, for example, Congress relied upon the State child protective services (CPS) agencies.

For reasons detailed below, the Commission believes that the P&A system should be brought into active involvement in efforts to prevent illegal denial of treatment to children with disabilities. In summary, the Commission envisions the following new approach:

- Prompt reports of suspected or actual cases of withholding of medically indicated treatment would still be required to go to CPS agencies, and CPS agencies would retain the authority and responsibility to investigate them. However, the State P&A agency would be notified by the CPS agency as soon as the CPS agency received any such report. The P&A would have access to the records obtained and information developed by the CPS agency. As a representative of the interests of the child, the P&A agency would have independent authority, similar to that now held by the CPS agency, to obtain medical records and to obtain a court order for an independent medical examination. Further, the P&A agency would have independent standing to initiate a court proceeding to authorize medical treatment for the child, in addition to possessing standing to appear on behalf of the child in any court proceeding to authorize medical treatment initiated by the CPS agency.
- To catch cases that are not being reported to the CPS agency, any hospital that uses a committee to review a prospective instance of withholding of treatment from a person with a disability would be required to notify the State P&A agency of meetings held to discuss the case. The P&A would then be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee. If the P&A deemed it necessary, it could obtain a court order for an independent medical examination. If the P&A concluded that medically indicated treatment would be withheld illegally, it would have the standing to institute a court proceeding to require that it be provided.
- To provide a deterrent to physicians who not only might fail to report a case of withholding to the State CPS agency but also might not submit it to a hospital committee, the P&A would have

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[8] *Id.* at 5, 13.

[9] National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 3 (1988).

[10] *See* 42 U.S.C.A. §6042(a)(2)(A)&(B) (West Supp. 1988).

[11] Telephone interview with Jim Baugh, Managing Attorney, Coalition of Advocates for the Disabled (Dec. 1, 1988).

[12] National Association of Protection and Advocacy Systems, 1986 Annual Statistical Report, App. III at 4 (1988).

[13] National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 18 (1988).

authority to conduct retrospective reviews of the medical records of those with disabilities who die in the State. If instances of illegal withholding of medical treatment were detected, the P&A could seek appropriate action by licensing boards or Federal funding sources; in extreme circumstances, it could institute suits for injunctive or monetary relief or refer cases for investigation by prosecuting attorneys.

The Commission sees several advantages to involving the P&A systems more directly in the enforcement of the Child Abuse Amendments of 1984.

First, and perhaps most important, the P&A system has far more specialized experience in safeguarding the rights of persons with disabilities than does the CPS system. Although the CPS system deals with the abuse and neglect of all children, most of whom are not disabled, the P&A system since its inception has concentrated on protecting the rights of persons with disabilities. As chapter 10 documents, there is a disturbing tendency among CPS workers to evince many of the negative attitudes and pessimistic views concerning people with disabilities that are prevalent in the society as a whole. Because of their greater experience with persons with disabilities, and the knowledge and sensitivity they have thereby acquired, it is only natural that P&A workers are on the average more likely than CPS workers to be vigorous, effective, and reliable advocates for the treatment rights of those with disabilities.

Second, the P&A system is less likely to be affected by conflicts of interest than the CPS system. CPS agencies are integral parts of the State bureaucracy, compromising their willingness or ability to take action against other State agencies, such as State hospitals, that may be alleged to be involved in treatment denial.[14] By contrast, the P&A system is statutorily independent of State agencies. The Governor of each State has the authority to designate the P&A agency for each State.[15] However, the 1984 Developmental Disabilities Amendments sought to ensure the independence of the system by requiring "assurances. . .that the agency implementing the system will not be redesignated unless there is good cause for the redesignation and unless notice has been given of the intention to make such redesignation to persons with developmental disabilities or their representatives."[16] The Senate Labor and Human Resources Committee Report emphasized:

> The Committee is. . .concerned that any change in P&A designation within any jurisdiction be only for good cause. Such good cause does not, in the Committee's view, mean aggressiveness—specifically litigation against any agency of state or local government—in the pursuit of the designee's mandate to protect persons with developmental disabilities. . . .The Committee urges the Administration on Developmental Disabilities [the HHS unit in charge of supervising the developmental disabilities aspect of the P&As] to promulgate regulations and to carefully evaluate any redesignation request to assure that there is both good cause for any redesignation request and that notice of such request has been provided to clients and client groups within the jurisdictions of the appointing authority prior to the request being submitted to the Administration on Developmental Disabilities.[17]

Third, since CPS agencies rely heavily on the medical profession as the major source of reports of "traditional" child abuse and neglect with which they are primarily concerned, they are often reluctant to jeopardize that working relationship by appearing in an adversarial relationship in the context of alleged medical neglect.[18] Unlike the CPS agencies, the P&A agencies have no special relationship with the medical profession that would impair their ability to be vigorous advocates.

Fourth, P&A agencies are accountable to the populations they serve. They must provide an annual opportunity to the public to comment on their priorities and must have a grievance procedure "to assure that persons with developmental disabilities have full access to services of the system."[19] This provision for oversight, not present in most CPS agencies, is an important check on the danger of relaxing the vigilance and vigor essential to effective advocacy. The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987,[20] in the words of the Senate Labor and Human Resources Committee Report, added:

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[14] See chap. 10.

[15] National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 1 (1988).

[16] Developmental Disabilities Act of 1984, Pub. L. No. 98-527, sec. 2, §142(a)(5), 98 Stat. 2662, 2680 (codified at 42 U.S.C.A. §6042(a)(5) (West Supp. 1988)).

[17] S. Rep. No. 493, 98th Cong., 2d Sess. 29, *reprinted in* 1984 U.S. Code Cong. & Admin. News 4334, 4362.

[18] See chap. 10.

[19] 42 U.S.C.A. §6042(a)(2)(C)&(D) (West Supp. 1988).

[20] Pub. L. No. 100-146, 101 Stat. 840 (codified at 42 U.S.C.A. §§6000-6083 (West Supp. 1988)).

> several provisions designed to enhance the accountability of the protection and advocacy systems by: ensuring particular attention be paid to the needs of Indians and members of racial and ethnic minorities who are developmentally disabled; requiring the establishment of grievance procedures; and by providing the public with an opportunity to make public comment on the priorities established by the System.[21]

In the view of the Commission, therefore, it is desirable to make better use of the P&A systems to enforce the Child Abuse Amendments of 1984 and section 504, as well as other constitutional, statutory, and regulatory provisions protecting the medical treatment rights of persons with disabilities. To do so, certain tools are essential.

First, when a State CPS agency receives a report alleging the withholding of medically indicated treatment from someone with a disability, the State P&A should immediately be notified. At present, there is no provision for notification of the P&A. To enable it to make an independent assessment and, if deemed necessary, to take independent action to protect the medical treatment rights of the child, the P&A should have access to any information received or developed by the CPS agency. For the same reason, it should be given the authority to investigate the allegation, to designate medical professionals to review the medical records, and if need be, to secure a court order permitting these medical professionals to conduct a medical examination. It should have the authority to represent the interests of the child in any court proceeding, as well as independent standing to bring a court action to enforce the child's rights.

Second, access to medical records is essential not only when a CPS agency has received a report of denial of treatment, but also when the P&A independently receives a report. Medical records are the key source in evaluating the validity of allegations of illegal denial of treatment. As the American Bar Association's Model Procedures note:

> Records, if properly maintained, are the most objective data available. Interviews by themselves may be misleading, if persons alter, omit, or embellish facts. Also, records may reveal contrary views expressed by nurses, doctors and others. The medical records should provide documentary evidence of the course of the patient's medical evaluation, treatment, and change in condition, and of communication between the responsible physician and any other health professional contributing to the patient's care. The infant's medical record should specifically contain: (1) identification information; (2) evidence of appropriate informed consent or indication of why it is absent and what is being done to obtain the necessary consent; (3) patient's medical history; (4) report of patient's physical examination; (5) diagnostic and therapeutic orders; (6) observations of patient condition, including progress notes and nursing notes; (7) report of all procedures, tests, and their results; and (8) conclusions, including the provisional diagnosis, associated diagnoses, clinical resume, and necropsy reports.[22]

In 1984 Congress amended the law to ensure P&A agencies access to the records of institutionalized persons with developmental disabilities when complaints from or on their behalf had been received by the P&A and they had no legal guardian other than a blanket public guardian.[23] The 1986 legislation provided for access to the records of persons with mental illness under a more detailed but essentially similar standard,[24] and a correlative provision was inserted into the developmental disabilities law in 1987.[25] In circumstances in which denial of treatment to children (and often older people) with disabilities is in contemplation, however, the parents or other guardians have, typically, nominally consented to the treatment denial. It is essential, therefore, that in such cases the P&As have authority to obtain access to the records, with appropriate assurances of confidentiality, without requiring the consent of the guardian.

Third, to circumvent the documented failure of many hospitals to report suspected instances of withholding of medically indicated treatment that come before their infant care review committees,[26] new mechanisms are needed. Any health care facility that uses such a committee (or any other standing or ad hoc committee)[27] to review any prospective instance of withholding of treatment from a person with a disability should be required to notify the State P&A of any committee meeting to consider such a case. The P&A should be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee.

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[21] S. Rep. No. 113, 100th Cong., 1st Sess. 24, *reprinted in* 1987 U.S. Code Cong. & Admin. News 781, 803.

[22] Nicholson, Horowitz & Parry, ***Model Procedures for Child Protective Service Agencies Responding to Reports of Withholding Medically Indicated Treatment From Disabled Infants With Life-Threatening Conditions,*** 10 Mental & Physical Disability L. Rep. 220, 239 (1986) (footnotes omitted).

[23] Developmental Disabilities Act of 1984, Pub. L. No. 98-527, sec. 2, § 142(a)(2)(D), 98 Stat. 2662, 2679 (codified as amended at 42 U.S.C.A. § 6042(a)(2)(G) (West Supp. 1988)). *See also* S. Rep. No. 493, 98th Cong., 2d Sess. 30, *reprinted in* 1984 U.S. Code Cong. & Admin. News 4334, 4363.

[24] Protection and Advocacy for Mentally Ill Individuals Act of 1986, Pub. L. No. 99-319, sec. 105(a)(4) 100 Stat. 478, 480 (codified at 42 U.S.C.A. § 10805(a)(4) (West Supp. 1988)).

[25] Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, § 301(a)(3), Pub. L. No. 100-146, 101 Stat. 840, 852 (codified at 42 U.S.C.A. § 6042(a)(2)(G) (West Supp. 1988)).

[26] See chaps. 10 and 11.

Fears that such a notification requirement would lead to frequent adversarial confrontations and vexatious litigation are not warranted by the track record of the P&As. P&As have developed a tradition of resolving potential violations of the rights of persons with disabilities or mental illness without litigation. "These Protection and Advocacy Systems (P&As) served approximately 85,000 people in 1986, and have been successful in negotiating 97 percent of their cases without resort to litigation."[28] Vigorous rights advocacy does not invariably require adversary courtroom proceedings, and it may well be that the rapid involvement of the P&A advocates on a local level while decisionmaking is still in process and positions have not hardened will avert the need for confrontation in many instances.

Unlike most CPS agency workers, most P&A workers should be familiar with local and specialized parent support groups, sources of financial and inkind support and counseling, which can be shared with the parents, health care personnel, and internal hospital committee. (P&As are responsible for significant information and referral for persons with developmental disabilities.[29]) This may well lead to agreement on the part of all to follow a course of treatment in full compliance with the law. In this context, the language of the 1984 Senate Committee report is particularly appropriate: "The Committee commends the emphasis by P&A's on mediation and/or administrative remedies while at the same time recognizes that there will undoubtedly be future instances where litigation is the necessary alternative to protect disabled persons' rights."[30]

Fourth, to provide both a mechanism for evaluating compliance and a deterrent to violations, each State P&A should have retrospective access to the medical records of all children with disabilities who die. Presumably, in most States only a random selection would be routinely reviewed most years. However, authority should exist to review confidentially as many as the P&A deems necessary.

To ensure protection of the rights of institutionalized persons with developmental disabilities, Congress has already required that P&As automatically be provided annual survey reports on every intermediate care facility for people with mental retardation in their States.[31] The Commission considers this proposal to be a reasonable extension of that precedent. Requiring notification to the P&A whenever an infant care review committee convenes to consider a "live" case, standing alone, will probably ameliorate the widespread failure to report by health care facilities, but it is unlikely to cure it. Since the establishment of such committees is voluntary with each hospital, it will have no effect on those facilities without them. Beyond this, the effect of the notification requirement, if there were no retrospective access, might be to drive underground contemplated withholding of treatment, as physicians seeking to avoid outside review might simply cease to use the formal hospital committees. A knowledge that all deaths of children with disabilities will at least potentially be subject to retrospective review will significantly reduce that incentive.

Fifth and finally, the Commission agrees with what the Senate Committee wrote in a slightly different context: "Providing the resources necessary to match the mandate of the P&A systems is essential if the job is to be done."[32] Appropriate additional funding for the P&As will be needed to implement these new responsibilities. It should be adequate both for State-by-State implementation and for supportive training and technical assistance, including resources for the rapid evaluation of medical conditions.

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[27] A 1985-1986 survey of hospitals with 1,500 or more births annually or a neonatal intensive care unit found that even when no official committee is designated:

> In many hospitals an informal group structure is used. In 6.7 percent of hospitals, this includes physicians, specialists, and parents; in 5.7 percent, it includes a group of professionals in the hospital; [and] in another 2.5 percent of the cases it includes a group of physicians. . . .

R. Greenstein, S. Hudd & G. Fleming, National Collaborative Survey of Infant Care Review Committees in United States Hospitals 6 (1987). *See also* University of Connecticut Medical School/American Academy of Pediatrics, Project Summary[,] Infant Care Review Committees in United States Hospitals: A National Survey 2 (1987).

[28] S. Rep. No. 113, 100th Cong., 1st Sess. 10, *reprinted in* 1987 U.S. Code Cong. & Admin. News 781, 790. *See also* S. Rep. No. 493, 98th Cong., 2d Sess. 28, *reprinted in* 1984 U.S. Code Cong. & Admin. News 4334, 4361 (98 percent of FY 1982 cases resolved without litigation).

[29] 42 U.S.C.A. §6042(a)(2)(A)(ii) (West Supp. 1988).

[30] S. Rep. No. 493, 98th Cong., 2d Sess. 28, *reprinted in* 1984 U.S. Code Cong. & Admin. News 4334, 4361. *See also* S. Rep. No. 113, 100th Cong., 1st Sess. 10, *reprinted in* 1987 U.S. Code Cong. & Admin. News 781, 790.

[31] 42 U.S.C.A. §6042(a)(4) (West Supp. 1988).

[32] S. Rep. No. 493, 98th Cong., 2d Sess. 29, *reprinted in* 1984 U.S. Code Cong. & Admin. News 4334, 4362.

With these powers and resources, the P&A system would be in a position to bring about what the Commission believes would be a significant improvement in enforcement of the medical treatment rights of persons, especially children, with disabilities.

Chapter 14

Findings and Recommendations

The United States Commission on Civil Rights has undertaken to produce this report under its statutory mandate to "submit reports to the Congress and the President at such times as the Commission, the Congress or the President shall deem desirable."[1]

Nearly 7 years ago, the Nation's attention was captured by news accounts of the starvation of Infant Doe in Bloomington, Indiana. Details of that case as well as of many other cases of wrongful denials of medical treatment for children born with disabilities are contained in this report. The report has examined and found serious deficiencies in the implementation of the Child Abuse Amendments of 1984 and makes recommendations to remedy these deficiencies. Furthermore, this report provides evidence that was unavailable in the administrative record and that would have been useful to the Supreme Court in its consideration and subsequent invalidation of the Infant Doe regulations at issue in *Bowen v. American Hospital Association.*

In the course of its hearings on the subject matter of this report, the Commission received testimony from a wide variety of individuals, including medical specialists, persons with disabilities, ethicists, hospital administrators, Federal officials, parents, academicians, and representatives of disability groups. These hearings have been published separately.[2] Of the many statements the Commission received, however, an excerpt from the testimony of Robert Williams, deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens, who himself has a physical disability, perhaps best sums up the essence of this report:

> [T]he way to secure commitments [to improve the way people with disabilities are treated and the services they receive] is not. . .[to] suggest that care be withheld from newborn infants with severe disabilities until adequate funding is provided to help them obtain their maximum developmental potential. What benefit can result from this strategy? At best it can be seen as an extreme example of circular reasoning. At worst it can lead to the most vicious of circles. Appropriate support services necessary to assist the families of newborns with severe disabilities to love and care for their child in their own home will not be available as long as we devalue the life of a child so much that it becomes acceptable to withhold the most ordinary care.[3]

Based on its hearings, research, and this report, the Commission adopts the following findings and recommendations:

General Findings

1. Surveys of health care personnel, the results of investigative reporting, the testimony of people with disabilities and their relatives, and the repeatedly declared views of physicians set forth in their professional journals all combine to persuade the Commission of the likelihood of widespread and continuing denials of lifesaving treatment to children with disabilities.

2. The Commission is convinced that the evidence supports a finding that discriminatory denial of medical treatment, food, and fluids is and has been a significant civil rights problem for infants with disabilities. It is also persuaded that the available

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[1] 42 U.S.C.A. §1975c(c) (West Supp. 1988).

[2] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* (1985) (vol. I) & (1986) (vol. II).

[3] *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 272 (1986) (vol. II).

evidence strongly suggests that the situation has not dramatically changed since the implementation of the Child Abuse Amendments of 1984 on October 1, 1985.

3. The grounds typically advanced to support denial of lifesaving medical treatment or food and fluids are based on erroneous judgments concerning the quality of life of a person with a disability or on social judgments that such a person's continued existence will impose an "unacceptable" burden on his or her family or on the Nation as a whole. These judgments are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities.

4. Many people, including members of the medical profession, hold negative attitudes about life with disability that affect not only children but also adults with disabilities. Moreover, direct testimony was provided at the Commission hearings that these attitudes exist and that discrimination in the provision of lifesaving and other medical treatment occurs with respect to adults with disabilities as well as in cases involving infants and children. Further fact-finding is needed to determine the extent of discriminatory denial of medically indicated treatment in cases involving adults with disabilities.

5. There is evidence that in many instances in which lifesaving treatment is denied to children with disabilities, their parents are only nominally making the decision to withhold the treatment. In practice the doctors are often the prime movers in denying the treatment.

6. The question of whether children with disabilities should be denied lifesaving treatment has frequently been couched in popular debate as though the issue were the wisdom of government intrusion into matters of parental discretion. In fact, however, for decades the universally accepted law has been that when parents make treatment decisions that will undebatably lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating provision of lifesaving medical care. It is only when the children have disabilities that the claim of parental autonomy is given serious sympathetic consideration. Thus, the decisions upholding putative parental decisions to deny lifesaving treatment to their children with disabilities are rooted less in a respect for parental authority than in a bias against disability.

7. There are substantial economic costs associated with some forms of disability. Many costs, however, are less a function of the disability or the severity of the disability than of a policy that tends to segregate and isolate, at enormous public cost, those persons considered most severely disabled without even considering the alternative of providing social and economic support for the family. The assumptions influencing denial of treatment have often been: (1) that the level of severity of disability is the major determinant of lifetime costs; (2) consequently, that the more severely disabled a child may appear to be at birth the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency; and (3) therefore, the more expensive it will be to meet that person's basic needs. Although these assumptions rest on major fallacies, reliance on them has resulted in a self-fulfilling prophecy: a diagnosis of severe disability at birth leads to placements in residential and nonwork environments that significantly limit that person's capability and entail far more expense than necessary. The ultimate irony occurs when the expense that is the consequence of the original unfounded and stereotypical assumption becomes a basis for ending the lives of persons with severe, or what are thought to be severe, disabilities shortly after they are born.

8. The record developed during the Commission's two hearings and continuing investigation demonstrates that there is a grave danger to the constitutional rights of newborn children in cases in which food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. The principle of equal protection of the law is offended when disability is the basis of a nontreatment decision. Procedural protections for the interests of both child and parents are often absent completely or are woefully inadequate to the task of sifting the facts.

General Recommendations

1. The Commission concludes that the Congress and the President should address the very real problems faced by people with disabilities and their families. The President should take the lead in fostering the development of a climate of social acceptance of persons with disabilities and their families by speaking publicly on the issue. The President should instruct the White House Council on Domestic Policy to review the adequacy, as well as the coordination and development of, supportive services intended to assist such families. The President should order a review of the mechanisms designed for vigorous enforcement of the statutory rights of those with disabilities to accessible and integrated transportation, housing, education, health care, and employment. In addition, the appropriate committees of the Congress should schedule hearings to address these questions.

2. In considering legislation designed to prevent discrimination against persons with disabilities, Congress should take care to make clear that discrimination in the course of rendering medical treatment is precluded.

3. There is a need for factfinding activities by the Congress, the State legislatures, and Federal, State, and local agencies charged with the enforcement of civil rights laws and medical standards, to determine the extent to which adults with disabilities are subjected to discrimination in the provision of medical care and treatment, and to evaluate what remedies exist or are needed to prevent future discrimination of this kind from taking place. In particular, the new Secretary of Health and Human Services should direct the Department to undertake such a study.

Specific Findings Regarding Support for Families with Disabilities

1. The period surrounding birth is a time of considerable stress and emotion, and for nondisabled parents the birth of a child with a disability typically comes as a great shock. While beset by traumatic feelings of depression, grief, anger, and guilt, many such parents today have inadequate accurate information with which to make considered evaluations concerning the nature of life with a disability or the consequences for a family that includes a child with a disability.

2. One of the principal motivations for denial of lifesaving treatment to children with disabilities is the view that their continued existence will create too great a burden for their families. There is evidence that this concern has led to concurrence or acquiescence in the death or elimination of these children.

Specific Recommendations Regarding Support for Families with Disabilities

1. Congress should amend the Medicaid Act or other appropriate legislation to require that recipients of Federal financial assistance for medical services provide specific information on support and resources to parents of newborn children with disabilities. This should include information on adoption and, when necessary, information on other supported family placement with resources necessary to care for the child.

2. Congress should amend the Medicaid Act or other appropriate legislation to lower the adjusted gross income ceiling that a family must spend on disability-related medical expenses before the family member with a disability becomes medicaid eligible.

Specific Findings Regarding Section 504 of the Rehabilitation Act of 1973

1. The hearings and research conducted by the Commission, and the findings based on them, especially General Finding 5, supply a factual record that was absent in 1986 when the United States Supreme Court decided *Bowen v. American Hospital Association*, striking down regulations intended to assist enforcement of section 504 in the context of discriminatory denial of treatment to children with disabilities.

2. A central problem with the *Bowen* plurality opinion is that it suggests that section 504 puts no constraints on a recipient of Federal financial assistance responsible for the discriminatory denial of treatment to a person with a disability, if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child's medical treatment.

3. The Commission's findings suggest that parents who authorize denial of treatment to their children with disabilities are frequently substantially influenced in that decision by the views of their childrens' physicians and other health care personnel who frequently display inadequate awareness of the potential of these children.

4. In cases in which decisions nominally made by parents to deny treatment to children with disabilities are in fact generated by health care personnel, health care providers who do not provide lifesaving medical treatment to children with disabilities that would be provided were it not for the disabilities should be held to violate section 504 despite parental acquiescence in the treatment denial.

5. The logic of the *Bowen* plurality opinion applies equally to authorizations for denial of treatment by other nonrecipient surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions.

6. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities. In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient's involvement, would be prohibited discrimination. A recipient's substantial involvement in a nonrecipent's discriminatory practices should be held to violate section 504.

7. The Commission's reading of the legislative history and plain meaning of section 504 of the Rehabilitation Act of 1973 persuade it that the provision does cover discriminatory denial of medical treatment to people with disabilities.

8. The Commission concludes that passage of the Civil Rights Restoration Act establishes that a hospital's practice of reporting to State agencies instances in which parents withhold consent for provision of lifesaving treatment to their children is covered by section 504. The act defines section 504's coverage to include "all of the operations of. . .an entire corporation, partnership, or other private organization. . .which is principally engaged in the business of providing. . .health care. . . ." If a hospital engages in reporting cases of medical neglect to the State child protective services agency, that practice of reporting is among the operations of a corporation that principally provides health care. Therefore, if any part of the hospital receives medicaid or medicare, discrimination in reporting based on handicap (such as a practice of reporting instances in which religiously motivated parents refuse consent for lifesaving treatment for nondisabled children to the authorities, but failing to report instances in which parents refuse consent for lifesaving treatment for children with disabilities) violates section 504.

9. During the period in which enforcement of section 504 in this context was not yet enjoined, the performance of the Office for Civil Rights of the Department of Health and Human Services in implementing it was poor. Confronted with substantial evidence of significant and ongoing denial of lifesaving treatment to children with disabilities, evidence that suggested an ongoing threat to lives in two States, the responsible Federal agency failed to act with the vigor and dispatch incumbent on it in light of the circumstances, its legal responsibilities, and its publicly stated position.

Specific Recommendations Regarding Section 504 of the Rehabilitation Act of 1973

1. In light of the record developed by this Commission, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends that the Executive branch give careful consideration to resuming investigation of allegations that children with disabilities are discriminatorily denied medical treatment based on handicap and initiate enforcement of section 504 in cases in which the allegations are found to be justified.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to make clear that withholding of medically indicated treatment, as defined in the Child Abuse Amendments of 1984, constitutes denial of the benefits of health care services for purposes of Title VI and section 504.

Specific Findings Regarding the Child Abuse Amendments of 1984

1. The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care which States that receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

2. Parents engaged in life and death decisions for their children are heavily dependent on the good faith of, and accurate information provided by, those advising them. Because advisors may be ignorant or prejudiced about persons with disabilities, there is a need for the establishment of a broadly based advisory process that includes members of the local protection and advocacy system (P&As) and others with expertise in disability and rehabilitation. Establishment of a structured care review process or committee will ensure that the decision made is in compliance with the standards set forth in the Child Abuse Amendments, provided that any participant in the advisory process who is concerned with the well-being of the child has standing to invoke the remedies that are otherwise available under State law and the Child Abuse Amendments for dealing with child neglect.

3. Many State child protective services agencies rely heavily upon members of the medical profession for information and assistance concerning cases of parental child abuse. This close working relationship has also led to heavy reliance by many State child protective services agencies on the very medical care facilities and personnel whose actions, advice, or neglect are at issue in cases of suspected medical care discrimination. Taken together, such close working relationships among State child protective services agencies and members of the medical profession has resulted in the substantial failure of many such agencies to enforce effectively the Child Abuse Amendments of 1984.

4. It is questionable whether most hospital-based ethics or infant care review committees are constructed in a manner that makes them likely to conduct searching scrutiny of proposed denials of treatment. They represent an approach that relies essentially upon the internal self-regulation of the health care community. Few committees include representatives of disability rights groups; the majority convene only to deal with disagreements, rather than attempting to scrutinize most denial of treatment decisions to see whether they comply with the law. Instead of strictly applying the Child Abuse Amendment standards, many appear in practice to use more ambiguous criteria that include consideration of the projected "quality of life" of the child with a disability. Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

5. The Commission is dismayed at the poor performance of the Office of Human Development Services of the Department of Health and Human Services in fulfilling its responsibility to ensure that State child protective services agencies receiving funds under the Child Abuse Prevention and Treatment Act comply with the Child Abuse Amendments of 1984 so as to protect children with disabilities from illegal discrimination in the provision of medical care. That performance requires substantial improvement. Although the Commission is encouraged by steps the Office of Human Development Services now states it will take in response to this report, it is too soon to determine whether they will result in the very significant increase in scrutiny of the performance of recipient State agencies that is essential if the Department is effectively to fulfill its responsibilities under the law.

Specific Recommendations Regarding the Child Abuse Amendments of 1984

1. Because funds available under the Child Abuse Prevention and Treatment Act are apparently not sufficient to induce all jurisdictions to comply with the Child Abuse Amendments in order to qualify for them, compliance with the Child Abuse Amendments should be made an additional requirement for State eligibility for participation in medicaid, so that the protections they afford will be made available to all children with disabilities in the United States.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to establish a mechanism to improve reporting of cases of suspected withholding of medically indicated treatment by requiring that any hospital that uses a committee to review a prospective instance of withholding of treatment from a person with a disability is required to notify the State protection and advocacy (P&A) agency of meetings held to discuss the case. The P&A agency should then be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee. It should have authority to obtain a court order for an independent medical examination, and if it concludes that medically indicated treatment would otherwise be withheld illegally, it should have the standing to institute a court proceeding to require that it be provided.

3. Hospitals without a specialized advisory process for dealing with the special needs of parents for information on disability and rehabilitation should be required to establish a process in accordance with the provisions of the Child Abuse Amendments and the recommendation made above.

4. Representatives of the local protection and advocacy system should be included in the advisory process, both as advocates for the child's interests and as a resource for the information of the parents.

5. Congress should amend section 504 and the Child Abuse Amendments to require the establishment of such a care review process or committee within treatment facilities across the country.

6. Should any participant in a care review advisory process not be satisfied that the outcome of the process is in compliance with the standards set forth in the Child Abuse Amendments, that person should have standing to invoke such remedies, judicial or otherwise, that are available under State law for dealing with child neglect.

7. When a State child protective services agency (CPS) receives a report of suspected withholding of medically indicated treatment under the Child Abuse Amendments, it should be required promptly to notify the State P&A agency and to provide it access to the records obtained and information developed by the CPS agency. As a representative of the interests of the child, the P&A agency should have independent authority, similar to that now held by the CPS agency, to obtain medical records, to obtain a court order for an independent medical examination, to appear on behalf of the child in any court proceeding to authorize medical treatment initiated by the CPS agency. The P&A agency should also have independent standing to initiate a court proceeding to authorize medical treatment for the child.

8. To create a deterrent to physicians who not only might fail to report a case of withholding to the State CPS agency but also might not submit it to a hospital committee, the P&A agency should be given authority to conduct retrospective reviews of the medical records of those with disabilities who die in the State. If instances of illegal withholding of medical treatment are detected, the P&A agency should be able to seek appropriate action by licensing boards or Federal funding sources and, in extreme cases, to institute suits for injunctive or monetary relief or refer cases for investigation by prosecuting attorneys.

9. Congress should afford P&A agencies appropriate financial and backup assistance to enable them to fulfill these roles capably.

10. The Office of Human Development Services in the Department of Health and Human Services should take corrective measures to ensure more rigorous scrutiny of State plans submitted for funding under the Child Abuse Prevention and Treatment Act to remedy the current widespread failure of State child protective services agencies to comply with the requirements of the Child Abuse Amendments of 1984.

A Dissenting View on the Report *Medical Discrimination Against Children with Disabilities*

By William B. Allen, Chairman

When the *final draft* of this report was presented (and approved) by the Commission in January of this year, it did not contain any information whatever as to the rate of incidence of medical neglect of handicapped newborns. Nor did it include even raw numbers of the total births and deaths of severely afflicted infants in the United States. When I inquired, therefore, as to the dimensions of the problem, no one who had assumed responsibility for the preparation of the report could respond to me. I found this extraordinary, to say the least, and utterly unacceptable, to be candid. For that reason, among others, I voted not to approve the report.[1]

Since the Commission's final vote on the report, an appendix A has been added, reducing statistics from the Center for Disease Control from 1983 and partially responding to my inquiry. Nevertheless, those statistics do not accomplish all that I sought. In the first place, they provide no indication of what has occurred within the medical profession *since* the period of great concern about "Baby Doe" cases and since the enactment of the Child Abuse Amendments of 1984.[2] That is, they say nothing about the dimensions of the problem during the very years when this report was being prepared at a cost of half a million dollars! Secondly, no comparative analysis is provided of the various figures, and particularly those touching upon the three conditions most frequently adduced in this report. According to the 1983, and thus prereform figures, there were 3,093 live births with Down syndrome, of whom 84 died of the condition. There were 1,747 spina bifida births, of whom 95 succumbed. And there were 3,238 cases of *all* of the listed atresias, of whom 261 passed. The question remains: Are these numbers extraordinary? Of these deaths, what proportion might have been unnecessary?

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[1] That is to say, I abstained. I did not vote against the report, but neither did I vote to approve. Indeed, I spoke expressly in criticism of it. Mr. Destro finds this expression troublesome, despite the fact that the sentence, "I voted not to approve. . ." is exactly the grammatical equivalent of the sentence, "I did not vote to approve. . ." The point, of course, is that in the face of tremendous pressure, I do not palliate the significance of my vote by hiding behind technicalities. Rather, I candidly own that I voted not to approve, and would do so again on the record established here.

At his footnote 9 Mr. Destro worries not only about the grammar in my dissent but about my actual conduct in voting. To satisfy his curiosity in this regard, I now append to this dissent the full text I issued at the time I voted to abstain, entering an elision covering the material reproduced in the dissent (appendix 1). Suffice it to say that Mr. Destro's litmus, the Commission's "approach to the issue of medical care discrimination," falls wide of the mark of my observations. The question is not, or should not be a question of approach. It should be a question of actual contribution toward safeguarding vulnerable lives and rights. I indicated at the Commission debate, and now reaffirm, my belief that the Commission's "approach," far from protecting handicapped newborns, can only eventuate in making it more difficult to protect them.

The shortest path to the defense of handicapped newborns would be, not to carve out ever new exceptions to legal standards crafted over centuries, but rather to assure immediately the full range of protections to which persons are otherwise entitled. That would mean not new laws but confirmed enforcement of laws against homicide and entailing every ordinary gradation and distinction admitted in such cases. That is the import of my repeated—but still ignored—insistence, that handicapped newborns have the same rights all other persons enjoy—none more and none less.

[2] At page 208 Mr. Destro falsely characterizes my concern to know the facts as an attempt to get hard numbers on who committed what crimes. What I asked for, and I repeat, was simply a number indicating the incidence of handicapped newborns and a number of the deaths within that class. Mr. Destro finds it "incomprehensible' that anyone should seek such information. I am comforted, however, that staff was able to provide just that *(though without* comment) in the report's appendix A, and I am still more confirmed in my credulity by the fact that the Inspector General's 1987 reports from the Department of Health and Human Services make a fine effort in that direction.

What I find "incomprehensible" is that our staff and the subcommittee read and commented on the HHS reports, but nowhere attempted to come to terms with these numbers. That the reader may not suffer from the omission, I add those *brief* reports as appendices to this statement (2 and 3). Let the readers judge what the so-called "hard" evidence suggests, and I will be surprised if they come to any conclusion other than that the effort expended to "justify" a defective report could well have produced a better one if well directed—directed, that is, towards the report's own announced purpose: "to determine the nature *and extent* of the *practice* of withholding medical treatment or nourishment from handicapped infants." (Report, 1.1)

In short, I remain convinced that this report reflects all too prominently a certain kind of research incontinence. The failure to make as strong a demonstration as possible reflects only one side of that methodological flaw. On the other side has been the steadfast refusal to vent the report among critics in advance. When (as an *ex officio* member) I proposed last fall that the draft be sent out to interested parties for confidential comment, the drafting subcommittee refused. That meant that we had no means to measure the sufficiency of the report's representation of the "other side." The interest of producing the strongest possible counterargument is to enhance the credibility of the final document. As a matter of practice, Commission reports should always be expected to contain the most sympathetic representation possible of the strongest counterarguments to the positions taken. Even when such an approach will not guarantee that we persuade others, it will guarantee that we will earn their respect.[3]

Apart from these methodological considerations, I have previously written of substantive concerns that troubled me. The editing of the "final draft" has only partially relieved those substantive concerns. I remain persuaded, however, that the interests of handicapped newborns have been sacrificed to a political mission. I do not require in this space to repeat those arguments.[4] I believe at this moment that the most urgent contribution I require to make is to make clear the argument to which those who would defend handicapped newborns must respond. To that end, these remarks will be followed immediately by the commentary of Dr. Tristram Engelhardt, perhaps the foremost medical ethicist in the United States. Dr. Engelhardt prepared his evaluation of the report at my request and on extremely short notice, since I was not free to send it to him before it became public property.

Relative to Dr. Engelhardt's testimony about the incidence of undertreatment of handicapped newborns, it is regrettable that we are unable to make a judgment based on this report. With respect to his more substantive arguments, some I find reassuring, while disagreeing with others. In particular, I am not so sanguine as he about the power of the Hippocratic Oath to guide physicians through these trials. Because I discussed that central point in my previously published comments, I will produce that discussion here, to conclude my remarks, and then permit Dr. Engelhardt immediately to respond.

Life and Health the Ends of Medicine

The reason Hippocrates came to my mind during our preliminary discussion of discrimination against handicapped newborns was that much of what I read, and much of what was presented before us, seemed to present the question as one about thresholds for humanity, as if protoplasm quickened into humanity on some measurable scale to which our art or science could point us. Hippocrates had taken rather a different view, one which founded knowledge and applicability of the arts on "knowledge of the nature of man in general." [*Regimen,* I, ii] That is, he made knowledge of the arts (of the end of the arts) to depend upon knowledge of humanity, while today we seem to do the reverse—no matter what side of the "Baby Doe" debate we fall on.

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[3] Mr. Destro misreads my statement and compounds his error by then declaring his understanding that I "subsume the question entirely into the realm of medical ethics." (Destro, p. 208, n.3) My statement so clearly rejects this contention, in advance as it were, that I will not belabor the point. I will pause only long enough to say that, by giving space to voices that were not heard in preparing this report, I do not endorse their views of course. I add here, as an appendix, the letter I received from the American Academy of Pediatrics, stating their views (appendix 4). Further, since I have specifically disagreed with Dr. Engelhardt's interpretation of the Hippocratic Oath, there really can be no honest occasion for anyone to misconstrue this. Perhaps now is also a good place to remind the unwary that the argument *ad Hitlerum* generally betrays a want of defensible principle.

[4] At page 211 Mr. Destro appropriates my observation, that this report does not substantiate its claims of widespread abuse, to a purported denial that medical professionals discuss euthanasia and other sanguinary approaches to human life. This sleight-of-hand is totally unjustifiable. Happily, however, it rather serves to blast than confirm his case. For, on the premise that people are surely doing what they say they would be willing to do, Mr. Destro concludes widespread abuse for which he adduces not one shred of *direct* evidence. Since most of the discussions he relies upon are academic in character, it would not be difficult to set right this sophomoric use of those discussions. Let it suffice, though , to note that it is akin to believing that cannibalism has been morally justified simply because philosophy and law professors use the lifeboat example! Even if every such classroom and journal in the country used the example *in speech* (and that is close to accurate!), we would still need evidence beyond the incident at Donner Pass to declare the *practice* pervasive.

This is curious, indeed. Those who defend for handicapped newborns a right to treatment, no less than they who deny it, seem to believe that medical art should not be informed by any notion of moral or human ends. For the former, this leads to a powerful emphasis on legal and administrative procedures to prevent the medical arts deciding questions not appropriate to them; while for the latter, it leads to emphasizing medicine as a neutral art that may serve any purpose medical consumers desire for themselves. The idea that medicine is a neutral art was certainly foreign to Hippocrates, for whom the art was informed by the idea of human health, and it was no less foreign to the generations of physicians who subscribed to Hippocratic standards.

What we must note today is that physicians no longer subscribe to Hippocratic standards, and certainly not to the Hippocratic Oath. That oath, among other things, contained the following pledge:

> I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. Similarly, I will not give to a woman an abortive remedy.[5] In purity and holiness I will guard my life and my art. [Kass translation]

If every American physician adhered to this pledge, there would be no Baby Doe problem. In fact, however, American medicine has replaced the Hippocratic oath with its own "Principles of Medical Ethics," which dropped altogether the opposition to suicide and abortion. This is the history that, more than anything else, creates our contemporary difficulties—the deliberate, conscious adoption of suicide and abortion as medical remedies.

In the United States, however, we depend not merely on the self-restraint of physicians. The organic law of our society proffers a guarantee of the right to life to persons, a guarantee that parallels the Hippocratic pledge. When, therefore, our physicians ceased to believe in the Hippocratic commitment, *they nevertheless were subject to the constitutional commitment.* What we are trying to do now is to measure whether and how the protections of law can make up for the loss of steady moral commitment.[6]

In this respect our report does us a disservice. By presenting the plight of the handicapped newborn as the logical development of unbroken historical antecedents—the legacy of bigotry in America!—instead of as a corruption of previous accomplishments, it depreciates not only the value of the Hippocratic standard but also the organic principles of our nation.

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[5] At pp. 211-12 Mr. Destro profoundly, and sadly, misconstrues the slight mention of abortion made in my original statement. (Can anyone fail to see the relevance of the Oedipus tale?) Following the improvident lead of Ms. Berry, Mr. Destro struggles vainly to separate the questions, never noticing that he attempts to cleave the physician's soul. For the burden of my observation was nothing more than to remark the reason for Hippocrates' coupling of the pledges not to render abortions and not to assist suicides. They are not two choices, but one; and they are not dilemmas at all, from Hippocrates' perspective. It is, in fact, the assumption that moral choice implies dilemmas that is most profoundly the cause of our unwonted tolerance of moral weakness. Dilemmas exist where grounds of judgment are unclear. If, in our reasonings, we cannot state clear grounds of judgment, as I have tried to do, we will make matters worse, as this report and Mr. Destro's comments do.

In that light, we might do worse than to recall Thomas Jefferson's admonition. Describing the moral sense that makes man man, even when some persons seem to lack that very sense, Jefferson turned to example: ". . .there is no rule without exceptions; but is false reasoning which converts exceptions into the general rule. Some men are born without the organs of sight, or of hearing, or without hands. Yet it would be wrong to say that man is born without these faculties, and sight, hearing, and hands may with truth enter into the general definition of man." (Letter to Thomas Law, June 13, 1814, ***Writings***, p. 1337, Library of America)

[6] This report is not about medical neglect, nor its corollary in civil law, medical malpractice. The law offers guarantees to all citizens alike in this regard, whether handicapped or not. "Mere" medical neglect is not a civil rights problem, whereas systematic and discriminatory medical neglect would be. It may seem strange to say, but it is nevertheless true that civil rights guarantee the *fair* distribution not only of advantages, but also of burdens. Hence, so long as medical neglect may fairly affect any citizen, without regard to handicap, race, gender, or other prohibited grounds, it could not pose a civil rights problem. Thus the task of this report has been to prove not only that the handicapped newborn is burdened, but unfairly so. That the report fails to establish even the threshold phenomenon in the post-1984 environment is a signal condemnation of the effort devoted to it and the taxpayer funds expended on it.

The report opened with a sensible awareness of this difficulty, affirming that the "equal protection clause. . .creates a nondiscrimination standard" while the "constitutional procedural (sic) due process rights also considered. . .presuppose an existing substantive benefit which they ensure may not be denied by processes that fail to meet standards of fundamental fairness." (Report, 1.3n) But it lost its way in the attempted application, trying to distinguish the medical decision from the fairness decision. "If kidney dialysis, for example, is withheld from someone because it is medically contraindicated, such a judgment is outside the scope of the Commission's purview." Good, as far as it goes!, but compare that confident statement with the following: "A judgment not to perform certain surgery because is person is black is not a *bona fide* medical judgment." The fact is, however, that one's being black routinely enters into medical judgments, and particularly in the case of kidney dialysis! We know that medicine decides against kidney dialysis in black people, based on a reported judgment of lower tolerance likelihood. The case of the handicapped is not less intricately wound up with medical judgments. These are debatable judgments, but not isolable judgments. The civil rights response to the kidney dialysis is shaping up to be a program of organ donor quotas—that is, a decision that the medical decision is simply wrong! (Report, 1.4 and n.5)

The history is also false in terms, to the extent that it denies generally humane social instincts toward the "feeble-minded" in the era prior to the emergence of 20th century nihilism and eugenics. Indeed, the 18th and 19th century prison reform movement (which gave us penitentiaries, houses of repentance) aimed as much to distinguish the criminal from the "feeble-minded" and the insane as to provide rehabilitation. The fact that these primitive reforms fell short of modern necessities—and may by our lights even seem blighted—can by no means diminish the significance of that liberal impulse which gave birth to them.

The report rightly condemns the eugenicist movement and Margaret Sanger. I do not need conversion on that score. It is nevertheless unsound to seek to derive the eugenicist movement from mere historical conditions or the cultural milieu. The significance of this observation becomes manifest when we reflect that at the heart of the report, we find an assumption of *deriving rights from needs* (cf., ch. 8, n. 63).

Rights are neither defined nor illustrated by needs, not for the handicapped nor any other category of Americans. The reason black people ought to enjoy equal rights of citizenship is not that most of them are poor. It is rather that they are human beings to whom the rights and arts of self-government pertain no less than to any other humans.

We have abiding confidence that a regime of equal rights is the surest relief for unmerited disadvantage. We reject the contention, however, that to relieve disadvantages *is* to guarantee equality of rights. Insofar as this report takes the opposite position on this crucial question, we should not approve it. The correct application of this principle to the handicapped is to assure that they suffer no further burdens (above all civil burdens) than are already intrinsic to their circumstances. (I might point out that there is also a moral corollary, namely, that occasion be left for other folk to be considerate.)

Attachments to Statement of William B. Allen, Chairman

Comments on the Recommendations Regarding Section 504 of the Rehabilitation Act of 1973 and the Child Abuse Amendments of 1984

By H. Tristram Engelhardt, Jr., Ph.D., M.D.*

At times the most well-meaning and intelligent of men and women, from the best of motives, come to see an issue in a distorted light. Frequently this is the result of circumstances that have skewed the process of data acquisition and interpretation. Unfortunately, this appears to be the case with regard to the report and recommendations concerning section 504 of the Rehabilitation Act of 1973 and the Child Abuse Amendments of 1984. The report appears to have been written under assumptions that are false and misguiding. The report does not appreciate that a major shift in attitude has taken place, which makes further Infant Doe cases such as that in Bloomington, Indiana, highly unlikely, but which has made child abuse through overtreatment more likely.

Because of a failure to appreciate the range of harms to which seriously ill newborns may be exposed (especially the risk of useless and painful overtreatment), the report erroneously suggests that the task is one of encouraging further overtreatment rather than making some judicious changes in the Child Abuse Amendments of 1984, so that they will not constitute a threat to the best interests of a significant class of very seriously ill newborns.

Nor does the report appreciate the kind of cooperation among parents, physicians, and child protective services agencies that will be necessary if our society is to adapt to an environment of rapidly changing high-technology medicine. In what follows I respectfully submit some substantive criticisms of the draft report and recommendations with respect to section 504 of the Rehabilitation Act of 1973 and the Child Abuse Amendments of 1984. The central thrust of my comments is that there is no evidence of significant undertreating of severely ill handicapped neonates since 1985. If anything, there is evidence of overtreatment. Moreover, were there evidence of the failure to provide indicated treatment, the proposed approach would not be the preferred solution to the problem. If the recommendations of the report are aggressively followed, the interests of seriously ill newborns will be imperiled.

The Bias Toward Overtreatment: Overtreatment Is a Form of Abuse

To begin with, I find matters as described in the report not to accord with my experience as a physician and a bioethicist, or with my conversations with neonatologists and with parents of children with severe disabilities. In particular, the bias since 1983 or at least 1985 has been to overtreat, not undertreat, severely ill handicapped neonates. In my experience, families often wish to discontinue treatment, despite the recommendations of the physicians to the contrary. Moreover, physicians, especially neonatologists, as well as a preponderance of lay persons, often have an exaggerated view of what can be contributed by intensive medical interventions.

Physicians whose careers are dedicated to the saving of human life, and who often must spend many grueling hours in attempting to save a child, tend to regard parents who wish to stop treatment as quitters, as individuals disloyal to the therapeutic enterprise. One sees this phenomenon in other areas of medicine such as cancer treatment, where patients are frequently aggressively overtreated, subjected to therapies that involve significant pain and suffering, but little if any real promise of extension of life. The difficulties in this regard have in particular been illustrated by the resistance to hospice care, where futile treatment is avoided in order to give more appropriate comfort care. The reason that it is often very difficult for health care givers to move from futile curative care to humane supportive care is in part due to their becoming so involved in a desperate hope to cure that it is difficult to recognize the limitations of medicine.

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The Distortion in Perspective Due to the Therapeutic and Technological Imperatives

Technology has a force and momentum of its own, often described as the technological imperative. People tend to apply a technology in medicine if it is available, even if there is no evidence that the application will benefit those who are treated. The technological imperative involves an augmentation of what can be termed the therapeutic imperative: the view that it is always best to treat aggressively. It is worth recalling that physicians aggressively bled patients for over 2,000 years, even though this treatment conveyed no benefit, expect perhaps for those suffering from acute congestive failure. It is very difficult for individuals to do nothing for a patient, even when doing something harms the patient more than it helps. It is because of this seduction born of the inclination to intervene that the Hippocratic maxim, "First do no harm [*primum non nocere*]," was articulated. This maxim was extraordinarily important, then as now, because physicians (and now hospitals) are not only inclined to treat aggressively because of vain hopes born of the therapeutic, now the technological imperative, but because they take money from and derive esteem from their roles as heroic therapists. Since we often unrealistically expect so much from medical treatment, it is difficult to appreciate how easily we as individuals and societies are seduced by the technological imperative. However, it is important to recognize that overtreatment, the use of treatment that causes more harm than benefit, is a form of child abuse.

The Misguided Tendency to Regard Criticism of the Child Abuse Amendments of 1984 as Hostility Towards the Handicapped

In reviewing the draft recommendations regarding the Child Abuse Amendments of 1984, along with the attached appendices and supporting information, I am struck by the underrepresentation of the critics of the Baby Doe regulations and the subsequent Child Abuse Amendments of 1984 and how their arguments are treated. The considered judgments of the President's Commission are by implication styled rhetoric (see chapter 6). Beyond that, there does not appear to be any testimony from an official representative of the American Medical Association or the American Academy of Pediatrics; at least their views of matters since 1985 are not given in the report. Moreover, there is a remarkable underacknowledgement of the criticisms in the literature about the Baby Doe regulations and the subsequent regulations published pursuant to the Child Abuse Amendments of 1984. Finally, substantive criticisms have been construed as hostile opposition.

It may seem somewhat out of place to suggest that criticisms of the Child Abuse Amendments of 1984 should be entertained at this juncture. However, it is important to recognize how ill-stated some of those requirements are. According to the current requirements, one is explicitly mandated, under certain circumstances, to provide treatment that rational and prudent decisionmakers would agree is inhumane, that is, conveys more harm than benefit. The current law would allow the nonprovision of treatment only if "(A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."[1] Rubric (C) would require inhumane treatment. That is, in cases where the treatment is not also virtually futile, it would require treatment that from the perspective of a reasonable and prudent observer would cause more harm than benefit to the person being treated.

Such an approach to treatment has generally been held to be unethical and immoral. The American Academy of Pediatrics, for example, has required the provision of treatment only when it is clearly beneficial. "When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be sole focus of the decision. These are very strict standards."[2] Moreover, the American Medical Association quite properly has emphasized the legitimate role of parents in deciding on the scope of treatment when that decision reflects a reasonable judgment regarding the best interests of the child.

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[1] Pub. L. No. 98–457, 121, 98 Stat. 1749 (1984).

In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks, and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected the parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.[3]

Finally, it is important to note that a major element of Western moral reflections regarding the obligation to provide treatment has drawn a distinction between ordinary and extraordinary care, which hs not been equivalent to usual versus unusual care, but rather which has been equivalent to that treatment constituting an undue or disproportionate burden, versus that involving only a proportionate burden given likely outcomes, and that is therefore obligatory. There are many articulations of this moral viewpoint, but a recent one of classical force was provided by Pope Pius XII in 1957: "normally one is held to use only ordinary means—according to the circumstances of persons, places, times, and culture—that is to say, means that do not involve any grave burden [*aucune charge extraordinaire*] for oneself or another. A more strict obligation would be too burdensome [*trop lourde*] for most men and would render the attainment of the higher, more important good too difficult."[4]

It is crucial that one recognize that such distinctions between ordinary and extraordinary treatment were never meant to focus simply on economic considerations. In contemporary medicine, physicians are usually reluctant to treat severely ill neonates when the therapeutic intervention is likely to effect more harm than benefit. The focus is on the best interests of the patient. There is primarily an intention to avoid painful interventions that have little prospect of saving life. The testimony in a distorting fashion suggests that the decision not to treat depends primarily on a prejudicial and biased appreciation of the future quality of life of the neonate. Instead, the inclination not to treat is usually based on the judgment that the treatment will itself cause more suffering than benefit.

Because of the failure to appreciate the contemporary guiding ethos of neonatal medicine (i.e., that there is an inclination to overtreat and the usual interest in not treating is based on a concern not to harm the neonate), there is also a failure in the report and its recommendations to take seriously negative appraisals of the Child Abuse Amendments of 1984. For example, in chapter 9, the article by Kopelman, Irons, and Kopelman is described as disclosing "widespread hostility to the standards of treatment adopted by the Child Abuse Amendments of 1984." The data are more accurately described as giving substantive empirical basis for criticizing those amendments. To use the word "hostility" is to suggest an emotional disposition to disregard the amendment. However, the Kopelman et al. article gives good grounds for agreeing with the Office of the Inspector General, which in 1985 concluded that the current regulations are sufficient and that "most states feel that existing child abuse and neglect procedures would have been adequate to respond to baby doe reports."[5] Indeed, in light of this statement it is important to put the Kopelman et al. report, published in the *New England Journal of Medicine*, in proper perspective. On the basis of a questionnaire sent to the 1,007 members of the Perinatal Pediatric Section of the American Academy of Pediatrics, of which 494 members (49 percent) responded, 56 percent agreed that "infants with an extremely poor prognosis for survival were being overtreated."[6] This is not a statement supporting a quality of life judgment. But it is an opinion made by expert physicians in the field that more harm than good is being done in the treatment of a certain class of severely ill neonates.

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[2] American Academy of Pediatrics, "Principles of Treatment of Disabled Infants," *Pediatrics* 73 (Apr. 4, 1984), 559.

[3] *Current Opinions of the Judicial Council of the American Medical Association—1984* (Chicago: American Medical Association, 1984), p. 11.

[4] Pope Pius XII, Allocution "Le Dr. Bruno Haid," Nov. 24, 1957, *Acta Apostolicae Sedis* 49 (1957), 1031. English translation from Pius XII, "Address to an International Congress of Anesthesiologists," Nov. 24, 1957, *The Pope Speaks* 4 (Spring 1958), 395-96.

[5] Office of Inspector General, Office of Analysis and Inspections. Survey of state Baby Doe programs. September 1987. (Pub. no. OA1-03-87-0018.)

There is indeed an inclination in the report to construe medical decisions as merely technical decisions regarding the likelihood of success or failure of a particular treatment. In medicine traditionally, and today in areas outside of the treatment of handicapped neonates, this has not been the understanding of appropriate medical decisionmaking. Appropriate medical decisionmaking has traditionally and still is generally held to include consideration of whether treatment will provide more benefit than harm. Indeed, physicians are morally obliged to refuse to provide treatment that produces substantially more harm than benefit. Insofar as the recommendations of the Civil Rights Commission undermine this ethos, one can only conclude that the recommendations as currently written will make matters far worse, not better, for the citizens, including the handicapped citizens, of the United States.

Is There Sufficient Protection Already?

Whatever may have been the state of affairs prior to the Baby Doe regulations and the Child Abuse Amendments of 1984, those changes in law and public policy combined with the ever-increasing level of exposure to malpractice litigation strongly bias physicians in favor of treating a severely ill neonate, even in cases where physicians believe such a treatment will be inhumane, will in fact involve more harm than benefit to the neonate who is treated. in addition, the issue of whistle blowing is radically different in areas of child abuse than in other areas of American society. Anonymous information can be provided to State child protective services agencies for investigation, so that the whistle blower is not placed at any risk. There is no analogy between the risk to whistle blowers currently making reports regarding child abuse and other areas of whistle blowing, where there is little possibility of anonymity nor an agency obligated and equipped to investigate anonymous reports.

The interaction between parents and physicians must be appreciated within this perspective. There are already substantive requirements to provide sufficient information to parents so that they can make an informed choice with regard to the treatment of their severely ill neonates. These requirements are already supported by substantial malpractice awards. In addition, the threat of being charged with child abuse has keenly focused the attention of physicians on the rights of severely ill children. To find that improper persuasion of parents by physicians occurs in this context is to judge that it is bad social policy for parents to rely on the best available expert medical care when needing to make decisions about the treatment of their children, bearing in mind the presence of subsequent sanctions against physicians, should they acquiesce in child abuse or provide improper treatment.

It may very well be the case that, in many areas, the best of physicians are not fully informed regarding likely prognoses. This will be a difficulty that medicine will face generally as technological progress accelerates, requiring accelerated and intensified continuing medical education. But this general problem is unlikely to be solved simply by heightening government-bureaucratic enforced interventions. A much more plausible alternative approach to this problem, which is not restricted to any one area of medicine, is to find ways of cooperating with and assisting specialty societies in the continuing education of their members. In short, *IF* physicians are still undertreating patients, it is unlikely that the measures suggested by the Civil Rights Commission will be a salutary remedy for this difficulty. Only by working with such organizations, trusting them and encouraging their trust, will the nuanced self-regulation be ensured, which is needed in such rapidly changing technological areas.

But this contention about undertreatment involves a very large IF. As the Kopelman and other articles suggest, the current climate supports overtreatment, that is, causing more harm to patients than good.[7] For example, Dr. Stuart F. Spicker (professor in the Department of Community Medicine and Health Care, School of Medicine, University of Connecticut Health Center), who, under a grant from the

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[6] Kopelman, Irons & Kopelman, *Neonatologists Judge the "Baby Doe" Regulations*, 318 New Eng. J. Med. 683 (1988).

[7] John C. Moskop and Rita L. Saldanha, "The Baby Doe Rule: Still a Threat," *Hastings Center Report* 16 (April 1986), 8-14.

Fund for the Improvement of Postsecondary Education, Department of Education, is engaged in an educational project to improve the functioning of hospital ethics committees throughout the United States, states that from his experience, "there is no indication from numerous cases discussed in the project by members of U.S. hospital ethics committees that there is any significant abuse of the rights of children as alleged by statements recorded in the U.S. Civil Rights Commission Report. There is no substantive abuse or endangerment of children that would justify the proposed additional interventions in established medical practice."[8]

Handicapped Neonates Should Not Be Obligatory Subjects of Medical Experimentation

If the therapeutic and technological imperatives are not contained, it will appear to be obligatory for physicians to apply experimental treatment to children, even if the treatment is considered inhumane, unless the results of that treatment are known to be virtually futile. The result is that at the edge of developing new medical technologies, physicians will find themselves obliged to subject handicapped newborns to treatment which would ordinarily not be permitted because of its adverse harm-benefit ratio, but which an overly zealous interpretation of the Child Abuse Amendments of 1984 would require. That is, the rapidly developing frontiers of medical technology will continually create opportunities to subject handicapped newborns to heroic medical and surgical interventions, where it will not be able to be shown that those interventions are virtually futile, but where a reasonable medical judgment will be that harms will outweigh benefits.

The Family as the Key to the Decentralization of the Authority of Experts in a Technological Society

Unquestionably, parents are highly influenced by the physicians they consult about treatment of their children. Nor will there ever be perfect physicians or perfect transfer of information to parents in circumstances where life and death decisions must be made. On the other hand, bureaucratically enshrined regulations and guidelines are unlikely to fare as well. Indeed, they are much less able to provide the nuanced, situation-dependent guidance necessary in areas of rapid technological advance. There is, as a result, a strong argument in favor of relying on the good will of families and physicians to make reasonable judgments, especially given the substantive societal restraints already in place.

One might observe that one of the major lessons to learn from Nazi Germany is that the government should not be given primary authority regarding life-and-death choices. Hitler's Germany, it should be recalled, both forbade abortions and enjoined euthanasia. The lesson of history suggests that the costs in the long run from relying on families are much less than relying on governments. This may explain why in the Federal Republic of Germany, where the lessons from the history of Nazi atrocities consciously guide contemporary public policy in order to avoid a repetition of those atrocities, there has been explicit effort to avoid rules such as those incorporated in the Baby Doe regulations. At a conference held in Germany, June 27–29, 1986, the German Society for Medical Law recommended that the physician be excused from providing treatment for handicapped newborns whenever:

(1) life cannot be maintained for any length of time, but instead one will only be postponing a certain death, e.g., in the case of severe dysrhaphia-syndrome or inoperable heart defects;

(2) in spite of treatment it is determined that the newborn will never have the possibility of communicating with his environment, e.g., severe microcephaly, very severe brain damage;

(3) the newborn's vital functions can be maintained for any length of time only by means of intensive medical intervention, e.g., breathing difficulties without possibility of restoring health, loss of kidney function without possibility of restoring health.[9]

These decisions should be made as far as possible with the family. The above recommendations were made not in order to avoid the continued life of handicapped infants, but rather to avoid therapeutic interventions that would cause more harm than benefit.

The decentralization of important decisions has been the genius of Anglo-American countries. One belittles the opinion of the plurality of the Supreme Court in *Bowen v. American Hospital Association* if one overlooks the implied criticism by the Court of government intrusions in family decisionmaking.

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[8] Personal communication, Jan. 8, 1989.

[9] Hans-Martin Sass, "Moral Dilemmas in Perinatal Medicine and the Quest for Large Scale Embryo Research: A Discussion of Recent Guidelines in the Federal Republic of Germany," *Journal of Medicine and Philosophy* 12 (1987), 287.

"Section 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children."[10] Here I think it is reasonable to see the Court in part reflecting the judgment that "The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children. This primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition."[11] To undermine this central role of parental choice is to depart substantially from the tradition of our law.

In this respect, the report seriously misstates the situation when it alleges in chapter 1 that only when children have severe disabilities is the claim of parental autonomy given serious consideration. In fact, parents are generally held to be free to choose any medical treatment endorsed by a recognized group of medical practitioners. This recognized right at law plays a substantial role when parents choose among different chemotherapeutic approaches for their children with cancer, often selecting a treatment that offers a reduced chance of survival, but involves less suffering and pain. Such choices are made regularly throughout health care and are considered proper, and are proper. Thus, one can see why the plurality in *Bowen v. American Hospital Association* emphasized that "it would almost certainly be a tort as a matter of state law to operate on an infant without parental consent."[12] The moral basis of this legal consideration would lead one to hope that, at the very least, the recommendation regarding section 504 of the Rehabilitation Act of 1973 would include a recommendation that no treatment be provided, other than on an emergency basis, over the protests of parents, without a court order.

Reliance as far as is feasible on parents choosing among acceptable medical options, which take into account the pain and suffering of severely ill neonates, will not in all cases provide protection to those neonates. But over the long run, such a policy will constitute a step away from a paternalistic elitist posture on the part of government and towards encouraging responsible choices by parents in consultation with their physicians and within the context of current legal protections. Still, one must observe that one of the reasons it is safer to walk in East Berlin at night than in West Berline is that the populace is more effectively monitored on the eastern side of the border. But that commitment to security has its own substantial societal costs.

The important point in all this is that, if we as a society are not to be enslaved to our medical technologies, we must help empower patients or their surrogates, not physicians or bureaucrats, with the authority to make the crucial decisions. We must as far as possible tolerate decisionmaking within the context of the family. Otherwise, democracies will be overwhelmed by the technological imperative. Democratic societies will succumb to the seduction of using all possible treatment, even when such treatment is inhumane or violates human dignity, that is, even when it is the source of more harm than benefit for those treated.

A State-by-State Approach to the Implementation of New High-Technology Medicine

A Federal system in which the States have different punishments for such serious crimes as murder and rape should easily tolerate a number of States exempting themselves from the Child Abuse Amendments of 1984. We as a society have only begun the serious task of developing policy for the application of high-technology, high-cost health care, which can often offer only limited promise of success but at the price of significant pain and suffering for the patients treated. There is unlikely to be one single morally appropriate way to make moral decisions regarding when such treatment should be applied. This is the case in medicine generally and with respect to the treatment of very low-weight neonates, as well as neonates who are born seriously ill with serious handicaps. Our Federal system can but benefit from the experience of those States that wish to forge their own approaches to responsible policymaking in these areas.

Quality of Life and Artificial Hydration and Nutrition

With regard to issues of quality of life, the report mixes apples and oranges. For example, in considering the role of quality-of-life assessments in chapter 3 of the December 2, 1988, draft, the report asks why so many support and practice the denial of lifesaving medical food and treatment. To begin with, reports such as Kopelman et al. demonstrate that the primary contemporary interest in restricting treatment involves cases of severely ill neonates where the course of treatment would be painful and inhumane to the child and the chance of success minimal, but not necessarily clearly "virtually futile." Moreover, the current interest in restricting hydration and nutrition primarily concerns neonates who have permanently lost consciousness. In this regard, it should be noted that the last Federal substantive examination of this issue led to the conclusion that "The decisions of patients' families should determine what sort of medical care permanently unconscious patients receive. Other than requiring appropriate decisionmaking procedures for these patients, the law does not and should not require any particular therapies to be applied or continued, with the exception of basic nursing care that is needed to ensure dignifiedand respectful treatment of the patient."[13] It should also be noted that medical care, at least in the case of adults, has been interpreted to include artificial hydration and nutrition. This considered recommendation conflicts with the holding of the Redwood County Court, Family Division, in "The Matter of the Welfare of Lance Tyler Steinhaus," which was substantively guided by the Child Abuse Amendments of 1984. There the county court required the provision of nutrition and hydration, although the child was permanently and irreversibly vegetative. However, an infant, or for that matter an adult, in a permanently vegetative state has no capacity to experience anything. Again, these cases are radically different from those that involve comparing different levels of the quality of life of individuals who have not permanently lost consciousness. The members of the Commission might consider what moral interests they would have in having their bodies maintained with artificial hydration and nutrition, were they permanently and irreversibly to lose all consciousness, and their next of kin approved the cessation of all treatment, including artificial hydration and nutrition. Whatever the Commissioners might consider, it should be clear that quality-of-life judgments in such cases are radically different from those that concern the "quality of life" of a perceiving, profoundly retarded child. In the case of a permanently and irreversibly vegetative individual, there is simply no quality of life whatsoever, so that the next of kin might very well properly judge that the provision of artificial hydration and nutrition would be an indignity that violates the moral and constitutional rights of the afflicted, which may then be protected through the choices of the next of kin. This view has increasingly been sustained by recent court cases, which have recognized a constitutional right to have such treatment refused. In this respect the report's consideration of constitutional issues is onesided at best.

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[10] At 647.

[11] Wisconsin v. Yoder, 406 U.S. 205, 232 (1971).

[12] At 630.

Fixing What Isn't Broken Can Harm Rather than Help

The proposed recommendations appear directed to a problem that does not exist; they are very likely to do much more harm than benefit to severely ill neonates. Moreover, they do not propose a realistic solution to the challenge of the continuing education of medical specialists, whose lack of current information would be the basis of a problem, were it to exist. Furthermore, there is a failure to take adequate account of the actual overtreatment of extremely ill neonates with poor prognosis for survival. To put the matter in perspective, one would need to talk to the numerous parents who have been forced to overtreat a severely ill neonate who dies despite a long, painful, and protracted therapeutic intervention.[14] In addition, one would need more sympathetically to review information such as that produced by Kopelman and others regarding the overtreatment of severely ill neonates. If one does not do this, one will run the risk of again forcing the critical judgment of the courts, as from Justice Leonard D. Wexler, who held that "the government has taken an oversimplified view of medical decision-making."[15] By proceeding as if massive abuse were occurring, one is likely further to encourage physicians to overtreat severely ill neonates who also have significant physical and other disabilities. Moreover, the acquisition of data and the review of medical records are not harmless endeavors. They not only are costly in terms of health-provider time and trouble, but can distract from the effective treatment of patients needing care. On this point, one should note that the original Baby Doe regulations spawned reviews of patient records that impeded the care of ill patients.

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[13] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C.: U.S. Government Printing Office, 1983).

[14] For a popular presentation of the plight of such parents, see Robert Stinson and Peggy Stinson, "On the Death of a Baby," *Atlantic Monthly* (July 1979), 64–65. Numerous discussions with parents have confirmed to me that their experience is far from unique.

[15] University Hospital, State of New York at Stony Brook, U.S. Court of Appeals of the Second Circuit, No. 6779, Docket 83-6343, Feb. 23, 1984.

In concluding, I encapsulate the foregoing reflections in terms of three general maxims:

1. Avoid seduction by the therapeutic and technological imperatives.

Just because a treatment offers some benefit of preserving life, it does not follow that it is a humane treatment. The actual pain and suffering involved in a treatment must be taken into consideration when deciding what treatment, if any, is indicated for individuals who have a good chance of dying.

2. Encourage responsible choices on the part of individuals and avoid the intervention of government bureaucracies, wherever possible, in individual life-and-death choices.

Given the complexity of modern medical technology, there is the temptation to generate new regulations rather than to rely on existing civil and criminal remedies. If our society gives in to this temptation, this will lead to a bureaucratization of medical technology, not to a responsible and informed citizenry who can use technology responsibly. This will make responsible choices more difficult and harm patients, not help them. Democratic societies should depart from already well-tested criminal and civil remedies only when there is clear and convincing evidence that current approaches are substantively ineffectual. One must find ways to encourage responsible choices by individual parents with their physicians regarding the treatment of severely ill neonates that minimize the intrusions of third parties.

3. Recognize that a treatment that has a chance of saving life may be appropriately declined, if the harms are likely to outweigh the benefits.

A good example is provided in adult health care by cancer of the pancreas, which has at best a 3 percent survival rate, subsequent to very aggressive surgical resection. However, the morbidity associated with the surgical attempt to cure is so great that many well-informed individuals, including physicians deciding for themselves, will reject the small chance of cure in order not to be subjected to very significant suffering in the remaining months of life. There is no reason to believe that courts would not allow parents to make analogous choices with regard to their children. There should be no restriction in the ability of parents to make such choices with regard to their newborn children, even if those children are born with serious physical and mental handicaps. There should be no obligation to provide inhumane treatment.

Appendix 1

EXPOSING OUR CHILDREN, EXPOSING OURSELVES

Comments on the Report
"Medical Discrimination Against Children with Disabilities"
of the U. S. Commission on Civil Rights

by

William B. Allen
Chairman

> TWO PHYSICIANS
>
> Doctor That's-Too-Bad, along with his colleague, Doctor So-Much-The-Better, went to see a sick man.
>
> The latter expressed hope while his comrade maintained that the bed-ridden patient was headed to his forebearers.
>
> The two being divided in mind for a cure, the sick man paid Nature's price. After which Doctor That's-Too-Bad seemed a prophet.
>
> Their profit rose further from the malady. The one boasted, "He's dead, as I well foresaw." -- "Had he believed me," said the other, "He would live well still."
>
> Fontaine

My colleagues hate it when I introduce literary, historical, or philosophical allusions. But Fontaine's little fable captures so evocatively the plight of the handicapped newborn, I cannot avoid opening with it. Perhaps seeing it written out will make it more bearable than merely hearing it read.

I comment on the disinclination to indulge my academic penchants because this is one case in which it makes a substantive difference in the report we are about to approve (and there is a majority of this body that has already indicated a resolve to approve it no matter what). Such a substantive effect emerged in our preliminary discussion last November. At that time I opened my remarks with the reflection that my reading of Hippocrates suggested a possible explanation of the difficulties. As the name Hippocrates fell from my lips, and just as swiftly, I discerned in the body language of my colleagues a considerable degree of frustration and bemusement -- so much so, in fact, that I detoured the comment I intended to make into innocuous channels and let the matter drop.

I now apologize for my faint-heartedness. While I expect the sympathy of everyone who knows how difficult it is to speak what no one wishes to hear, I recognize nonetheless that I had then an obligation to persevere. The fact that the question I wished to broach at that time looms still more ominously now reproaches my timidity. Accordingly, I will set forth succinctly the concerns that emerge from Hippocrates, before continuing with my appraisal of this report.

LIFE AND HEALTH THE ENDS OF MEDICINE:

. . . . .

RIGHTS NEITHER DEFINED NOR ILLUSTRATED BY NEEDS:

Rights are neither defined nor illustrated by needs, not for handicapped nor any other category of Americans. The reason black people ought to enjoy equal rights of citizenship is not that most of them are poor. It is rather that they are human beings to whom the rights and arts of self-government pertain no less than to any other humans. We have abiding confidence that a regime of equal rights is the surest relief for unmerited disadavantage. We reject the contention, however, that to relieve disadvantages is to guarantee equality of rights. Insofar as this report takes the opposition position on this crucial question, we cannot approve it. The correct application of this principle to the handicapped is to insist that they suffer no further burdens (above all civil burdens) than are already intrinsic to their circumstances. [I might point out that there is also a moral corollary, namely that room be left for considerateness by others.]

HANDICAPPED OR DISABLED:

Consider this more closely. Even the language we use is revealing. We must choose between the words "handicapped" and "disabled." There is an orthodoxy, to be sure. Nevertheless, where meanings count we remain free to question even orthodoxies. There is a difference between "handicapped" and "disabled" which is obvious -- namely, the one term is relative, the other absolute. A handicapped golfer is one who golfs, though never so well as another. To consult the terms alone, a disabled golfer is one who can not, or can no longer, golf. Disabled means to lack an ability, while handicapped means to possess an ability in qualified form. I have preferred handicapped in this general discussion because, in the matters that count (above all rights of citizenship), I am persuaded that the handicapped rather are abled than disabled, even if sometimes in qualified form.

If this reasoning be correct, then we can see the relevance of maintaining that rights are neither defined nor illustrated by needs. Insofar as rights relate to abilities or functions, they are defined rather by that to which the ability points than by the ability itself. But the ability is nothing other than the need, either actualized or in some state of development. The ability to take nutrition points to the right to life; the need for nutriment is the abiity to take nutrition either functioning or impeded in its functioning. Only what needs nutriment can have the ability to derive nutrition from sources of nutriment or to be impeded in that regard. Thus, only a being endowed with the right to life can have the ability to take nutrition and therefore needs sources of nutriment. We do not say, because a being needs nutrition, it has the right to life, except inductively. Nor, then, can we say, because a being needs nutrition, it has a right to sources of nutriment.

I will be prosaic: if doorways in buildings were characteristically just six feet high in our society, such that I would have to stoop to enter, it would not constitute the violation of any right I have, even though it were more commodious if I did not have to stoop. It would represent a need but not a right for me to have doorways tailored to my height, any more than it did, from the middle to the end of the 18th century, for George Washington, who stooped to pass through most doorways.

Architects and carpenters cut doors, when constructing buildings, to the general dimensions of the people who order them. Therefore, over time and in the aggregate, architecture and carpentry constructs buildings to what we might call an average of humanity. That average is not arrived at by looking at humankind altogether; it is arrived at by fitting the peculiar needs of the individuals who execute the orders. Over time through that process one will arrive at an average for all individuals, since most will fall within certain ranges.

This notion of the average of humanity, which the architect ends up approaching indirectly by serving the needs of the individual human, can be distinguished from the objective of health, that the physician consults. The notion of health is an absolute. It is certainly the case that in any given individual the physician has to inquire what condition of body and mind will be healthful. That inquiry, moreover, is carried out on the basis of a standard of health which is not in fact arbitrary or derived from the individual. The ultimate goal of health serves as a guide for the physician in elaborating such functioning of body and mind as makes it possible for the individual human being to attain the end of health. That human end has been described or defined for us in the Declaration of Independence and the American tradition largely as the "pursuit of happiness." What we may take than to mean is that the peculiar function of a human being is the pursuit of happiness, and that healthful functioning for a human being is to be able to carry on that pursuit with all of the abilities at the particular human being's disposal. We say, then, that for the human being health is not any given physical or bodily and mental or spiritual functioning. It is rather the harmonizing of physical and mental functions or abilities in the pursuit of happiness. Such abilities as any human being has, and insofar as those abilities can be properly harmonized in the pursuit of happiness, would denominate that human being a healthy human. Such a one would function in the ultimate way that humans function -- namely, in the pursuit of happiness.

On that kind of measure one can see that handicapped or nonhandicapped alike may all enjoy health. They do not require the identical capabilities physically or mentally in order that their capabilites may be harmonized in the pursuit of happiness. Insofar as this report denies that there is such a standard as health for human beings, it does not advance the cause of the handicapped. It rather undermines standards moral and physical for all human beings in general. It places the handicapped at a greater disadvantage by treating the standard of health as if it were arbitrary and merely subjective rather than fixed and absolute. Such a position would surely scandalize Aristotle and Aquinas, were they to see it set forth by students of theirs. And I must confess that it does no honor to this Commissioner to see it come from the staff of this Commission.

THE REPORT:

Our report, in its own words, "focusses solely on questions of discrimination." [p. 3] This is the correct posture for the Commission on Civil Rights, seeking to carry out its mandate under laws enacted by Congress. But that noble profession is belied by the note [#4] which addresses "the legal right of children with disabilities to receive equal treatment." This might represent only an infelicity of language. It concurs, however, with the language at page 17, which maintains

> Treatment decisions resulting in the denial of lifesaving medical treatment to children with disabilities cannot be viewed in isolation. Together with discrimination in employment, barriers to access to transportation and physical facilities, and a tradition of institutionalization, these decisions can only be understood in the context of longstanding attitudes and practices toward people with disabilities.

I believe that this is false; while it is true that discrimination against handicapped persons has been pervasive, it is not true that it has been systematic. Further, there is present here the common fallacy of subjecting ancient reforms to the modern standard of criticism, finding them wanting, and then concluding that they must have proceeded from ill motives.

This is the very argument -- the right to equal treatment, based on historical deprivations -- which I said above creates problems in our understanding of civil rights. In this case, it obscures the responsibility of physicians and hospitals. In the Carlton Johnson case, for example, we focus on procedures, when erroneous judgment was at fault. These kinds of decisions are not medical decisions -- they do not take life and health as their end. And just as the one most skilled at concocting an antidote is also the most successful poisoner, here we see the technology and judgment of medical pratictioners warped out of its natural order. I believe our report needs to tell us how this came to be, but it does not.

To undertake that mission, however, would have meant forswearing the attack on ideas of "normality." We cite testimony attacking that standard at page 18 (ch. 1), and in note 34 our own language, indicating that "society" structures its tasks and activities unfairly, shows the extent of our agreement with it. But society does not structure its tasks and activities. Men and women structure their tasks and activities, as architects and carpenters build for particular individuals. Society is nothing other than the resulting aggregate. There is of course a spectrum of abilities, and such a spectrum by definition must express a statistical norm. When folk say there is no normal they might just as well insist that "reality is whatever we say it is." Those two statements have the same truth value. That kind of radical subjectivity is fundamentally nihilistic and ultimately incompatible with a stable moral order.

My principal reason for objecting to the attack on the idea of normality is that we know that the ab-normal contains genius as well as deficiency, and we normals are unable to distinguish them. The purpose for attacking the distinction seems to have been the just desire to remove arguments from those who would support "elimination of people with some disabilities" [p. 58, ch. 3]. The handicapped would derive greater protection, however, from being integrated with normal people on the score of humanity than from attempts to deny the obvious. Consider: All newborns are thrown on the resources and care of their parent(s). Thus, in the absence of medical/community care, most would survive on the combination of parental love and their own eventual natural abilities. On those grounds, many of the handicapped also would survive. Some, however, would not (just as many of the normal children would not). Then arises the question, what affects the prospects of those who would not survive, whether handicapped or normal? To answer that question, we introduce medical science and community care. It turns out that art -- medical science -- can supply much of what is needed to fight off pneumonias and other life-threatening menaces. Thus, the parent once informed, the initial love is bolstered by access to arts otherwise not imagined. This process should differ not at all for the handicapped child and the normal child -- it is the normal process!

HOW TO AVOID INVIDIOUS DISCRIMINATION:

If the goal of protection for handicapped newborns is to assure them access to the normal process of nurture and care, and to avoid subjecting them to unfair civil burdens on the basis on their handicaps, then we have a strong basis for issuing a report that calls for changes in the way we do things. This report has done an excellent job of case-building. It is a work of advocacy rather more than a dispassionate analysis. As a work of advocacy, it is not a sufficient basis for every judgment and recommendation we might care to make. Nevertheless, enough evidence is apparent here that we are enabled to to tackle certain egregious oversights in the legal framework through which we seek to protect the rights of handicapped newborns.

The report lists fourteen recommendations for action. Among those fourteen one does not find the one which I regard as most urgent and, likely, most efficacious. Since the Hippocratic Oath no longer exists for us apart from the organic law of this republic, it is extremely important that we subject medical practitioners to the judgment of American law in light of the promises of those organic principles. Congress possesses and has before exercised every power required to make good the pledge of the Fourteenth Amendment. The Section 5 powers of Congress inform the Child Abuse Amendments.

FIRST RECOMMENDATION:

Those powers were not exercised in such a way as to guarantee that we could assure ourselves that the rights of handicapped newborns were being protected. Yet, nothing is more common in our society than the meticulous reporting of births and deaths! It would require little in the way of additional expense, and still less in labor, to require that the births and deaths of handicapped newborns, with notation as to course of treatment, be systematically reported to the Department of Health and Human Services. We have opted instead for a cumbersome, jerry-rigged structure of monitoring that consumes resources and delivers next to nothing by way of sevice. To my mind, this would be the most valuable recommendation we could make, *a universal reporting requirement*. This requirement, I must add, is nothing unusual, paralleling what many firms are subject to in other respects with EEOC or OFCCP or other agencies.

RECOMMENDATIONS IN THE REPORT:

I concur with recommendations 1 and 2 and 4 through 7, though not always for the reasons set forth.* I dissent from recommendations 3 and 8, as expressive of the author's intention to reinterpret the language of "equal protection" into a language of "equal or better treatment." I agree with the thrust of recommendation 4, but doubt the Commission's jurisdictional basis for making it.

Concerning recommendations 9 through twelve, I regard the entire P & A structure which they seek to strengthen to be misconceived in the important respect that, as the record here shows, they elaborate a system whereby the rights of handicapped newborns are made tenuous and imperilled by the apparent substitution of procedural for substantive fairness. The P&A responsibilities under the Child Abuse Amendments would make greater sense if, independently, someone were maintaining the applicability of substantive standards. That would be the case under a universal reporting requirement which facilitated routine monitoring. A system of intervention (the P&A system is relevant only where guarantees to govern intervention are evident) must be understood as a system to protect life, not to judge it. The current system operates primarily to provide a framework for making life-death judgments, and our procedural recommendations do not change that. The problem becomes apparent when one notes that the P&As are hip deep in medical judgments (and criticized for not making them well), although this report maintains that we aim to isolate problems of discrimination from medical judgments.

CONCLUSION:

I said above that it causes me distress to receive from the staff of this Commission a report which treats health as an arbitrary and subjective standard. But I do not entirely blame the staff; I have to assume that what they have done is to react to what they have thought others desired, rather than to think originally about how it is the handicapped may come to enjoy the rights of persons guaranteed in the Constitution and the Declaration -- the rights persons have to be treated individually in terms of the firm objective of the pursuit of happiness and therefore of health.** Others not understanding that could perhaps be led to make demands ostensibly in the interests of the handicapped, though in fact harmful to them.

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* These are the recommendations as set forth in the "Introduction." The recommendations are numbered differently in the concluding chapter, and there are two more besides!

** This is certainly to be expected when the work of an independent commission such as ours comes to be captured by advocacy groups, as this has been. The very process which, last September, I described as harmful in the extreme to this agency's prospects for making a meaningful contribution to our nation's future, seems to have been the process by which this report was produced. Some say what's good for the goose is sauce for the gander. I think it the very poison. If we have any saving grace in this hour, it is that some of us remain sufficiently alert to sound the alarm. It will not happen again!

I derive this hint from the many communications I have received in recent days from organizations urging me to approve this report without having read it and indicating thereby that for them the ideas are not what count. They seem under the spell of the view that there is a kind of politics, a kind of lobbying that is essential to defend fundamental rights and which transcend the actual content of those rights. Whether they accept the view of our staff that rights are positive and developmental (historically developmental, that is) as opposed to being inalienable and fundamental, I cannot say. They certainly accept the view that we do not require to think much about them in order to defend them.

This Commissioner cannot accept that view. I telephoned the author of the first of these letters and inquired whether he had read the report; he responded that he had not, but that he was taking the work of someone who has read it, someone here at the Commission, and whom he trusts. Now we all know that it is important to be able to trust people when we make certain kinds of practical and moral judgments. For no human being is capable of reviewing all the facts and circumstances that come to our attention and demand a moral judgment. But, having said that, one must add that it is therefore essential that the persons whom we trust indeed deserve our trust, that they possess such capacities mentally and morally as to make us confident that we are not likely to be led astray. Whoever it be my correspondent trusts here at the Commission clearly does not rise to such a standard of ability -- and perhaps not of honesty -- as to have merited that trust.

I assume that my correspondents do not trust me. After all, they do not know me, and what they have heard of me concerning this report is a lie. But what I have to say, I say not to gain their trust but to serve the cause of truth. I can think of no better way to emphasize to you how that operates than by returning to a frequent source of ore for my reflections -- Abraham Lincoln.

As I said at the outset, this report is going to be approved today. It's going to be approved without my having had serious opportunity to contribute to its shape or structure. I am just proud enough to be reluctant to add my name to anything that I have been denied occasion to shape -- not that I lack time, not that we lack the opportunity at this Commission, which is here today, will be back next month, and, as everybody knows, will be here through this year, but -- because others have willfully structured the process with the purpose in mind to deny me such an opportunity. Having been denied that opportunity, then, I will attach this statement to the report -- and I will do it in the spirit of Abraham Lincoln, in that spirit he expressed in the "Subtreasury Speech of 1839" and with which I now close:

> It *may* be true; if it *must*, let it. Many free countries have lost their liberty; and *ours may* lose hers; bit if she shall, be it my proudest plume, not that I was the *last* to desert, but that I *never* deserted her. . . I cannot deny that all may be swept away. Broken by it, I, too, may be; bow to it I never will. The *probability* that we may fall in the struggle *ought not* to deter us from the support of a cause we believe to be just; it *shall not* deter me. If ever I feel the soul within me elevate and expand to those dimensions not wholly unworthy of its Almighty Architect, it is which I contemplate the cause of my country, deserted by all the world beside, and I standing up boldly and alone and hurling defiance at her victorious oppressors. Here, without contemplating consequences, before High Heaven, and in the face of the world, I swear eternal fidelity to the just casue, as I deem it, of the land of my life, my liberty and my love. . . Let none faulter, who thinks he

> is right, and we may succeed. But, if after all, we shall fail, be it so. We still have the proud consolation of saying to our consciences, and to the departed shade of our country's freedom, that the cause approved of our judgment, and adored of our hearts, in disaster, in chains, in torture, in death, we NEVER faultered in defending.

APPENDIX

AN EDIPUS COMPLEX TOWARD LIFE
(An Essay, as it appeared in THE CRA NEWS, fall 1986)

Abortion deprives us of the deepest instincts of humanity. This is the conclusion which lies at the bottom of the heated debate which still rages within the United States and ought to stir the world itself. From the racist, eugenics-oriented movements which introduced the idea of systematic abortion early in this century, to the current righteous defense of indifferent abortion, the results are the same: they rest on the premise that we can become dull, insensitive to the claim of humanity which is at stake.

The preferred philosophical base of pro-abortionists resembles the Oedipus prophecy -- there are exceptional cases in which humanity itself recoils from demanding that a pregnancy be carried full term. Rape, incest, and deformity usually head the list. This kind of reasoning has a glaring default. It will be understood best if one rehearses the college philosophy example of the life-raft scenario. Two persons adrift at sea on a life-raft are starving. Their chances are minimal at best and absolutely nil if nourishment is not found. In that situation, is it just that one of the two might resort to canniablism (eating the other) in order to have any chance at all of surviving? Generally, everyone answers yes, just as most people are inclined to say, "yes, in the case of incest I can conceive of abortion as at least a justifiable homicide." Ought we to conclude from this exception, however, that the general moral rule must therefore admit the propriety of cannibalism or abortion in any case? Clearly that is not so, and we require above all today to make clear why it is not so.

When a decade ago I asked the "right to life" movement to speak of the "unborn child" instead of the "foetus", the motivating idea was that language plays an important role in focussing our moral antennae and such a tactic was needed to fend off the insensitivity with which we were surrounded. I continue to believe that this is necessary, but we now require more than words, we need to resurrect an entire humanitarian tradition in order to prevail in this struggle.

moral distinction. A girl is a human being! No one who has ordered the death of his unborn girl can claim to have any doubts about her humanity. What he is saying to us is that he prefers boy humans to girl humans. As occurs so often in human affairs, we discover in the practical arts of human beings a much surer guide to answering difficult moral questions than in mountains of abstruse scientific disputation. While the scientists continue to debate about just when the onset of humanity occurs, the people of South Korea demonstrate that they know full well: namely, from the moment one can determine the unborn child's gender!

One would imagine that this discovery merited headlines and huzzahs: The long sought answer found! Unborn child determined to be human boy or girl! Supreme Court now has guide to follow! But no. The news is rather different. "S. Korean Parents Tip Birth Ratio." "In the first ten months of the year, there were 117 male births for every 100 females." Normally, male births outnumber female births only slightly, and the numbers are evened up later by a higher mortality rate among males. One of the Korean doctors who sounded the alarm, Dr. Roh Gyung Byung, declared it "a terrible situation," and rightly so.

Nothing demonstrates the necessity of this conclusion so strongly as the recent report from South Korea, that selective abortion is there being practiced to indulge social prejudice about the preferred gender of offspring. Unborn girls are being aborted to make room for boys in South Korea. One needs to pause and think over the implications of this. The progress of modern science has made possible a pre-term identification of gender in the unborn child. What has followed is this systematic abortion -- a eugenics. But don't stop there. Note that the very idea of identifying a child's gender entails a necessary

Do we understand, however, just how terrible it is? This story is in fact confirmation of just how low we have descended in the scale of humanity. Abortions are not new to mankind. Mankind, however, have not always been so insensitive to them. The classic story of abortion -- exposure of the unwanted infant -- was written by Sophocles and inspired Sigmund Freud with the lynchpin of his psychological theories, the Edipus complex. Sophocles' Oedipus was to be exposed just after his birth, but the nurse entrusted with the chore could not look upon the "bundle of joy" with the required callousness. Rather than leave the child to the tender mercies of wild beasts, she left it in the care of a peasant who raised him to a mature humanity. The tragedy which resulted for Oedipus' family has often been misinterpreted as resulting from the nurses' tenderness. A more understanding reading would show that it derived rather from the decision to abort -- an attempt to avoid a prophecy of tragedy, which misread the prophecy as referring to events yet to come and not to the character of the very persons who attempted the abortion.

The children who are exposed today are less fortunate. They never meet with such nurses as Oedipus' even when they might have a chance of being raised to mature humanity by strangers. Despite the feeble efforts of government to mandate care for aborted children who, with the assistance of science, might yet survive, the prevailing moral climate produces virtually no examples of such heroics. Is it not clear that the child who is exposed by being ripped from the womb is at a great disadvantage compared to Oedipus? Those whose souls would have to resonate with the instincts of humanity are already dulled into insensitivity by the very operation through which they eliminate the child.

The modern world cannot depend on second thoughts to preserve the instincts of humanity. Modern science leaves no room for second thoughts. Lest we are to part forever from the tradition of humane caring, we have no alternative but to place abortion itself under a severe proscription. The Edipus Complex -- a son's rivalry with his father and love for his mother and its converse, the Electra Complex -- acquires a perverse meaning in a world in which fathers and mothers make the choices which South Korean parents are now making. The new Oedipus must die, unless we collectively, as a generation, make a commitment to him before he is exposed to the danger. This is the possibility we now await, assuming that he is not already among the lost.

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Appendix 2

SURVEY OF

STATE BABY DOE PROGRAMS

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[Executive Summary and Appendices omitted.]

INTRODUCTION

The term baby doe refers to a severely disabled infant with a life-threatening condition who is denied appropriate medical treatment. Two highly publicized court cases called national attention to baby doe in the early 1980s, and led to Federal legislation to protect the rights of such infants.

In the first case, an infant known as Baby Doe was born with Down's syndrome and a surgically correctable blockage of the esophagus. The baby's parents and doctor agreed that surgery should not be performed and that food and water should be withheld from him. The hospital sought a court order to permit surgery, but the court upheld the parents' decision, and the State supreme court refused to disturb the lower court's ruling. Baby Doe died before the case could be filed in the U.S. Supreme Court.

The second case involved an infant known as Baby Jane Doe, who was born with multiple neural tube defects, including spina bifida (an open lesion on the spine), microcephaly (an abnormally small head), and hydrocephaly (an accumulation of fluid on the brain). The parents approved medical treatment to reduce the chance of infection, but refused surgery to close the spinal lesion and drain excess fluid from the baby's brain. The parents' decision was later upheld by the State courts. It is not known what became of Baby Jane Doe.

In March 1983, the Department of Health and Human Services (HHS) published an interim final rule stating that section 504 of the Rehabilitation Act of 1973 applied to handicapped infants and establishing a Federal hotline for reports of failure to feed and care for such infants. One month later, the interim final rule was struck down in U.S. District Court. The Department published revised proposed regulations in July 1983 and final regulations in January 1984. These final regulations were struck down in U.S. District Court in June 1984.

The two baby doe cases and the subsequent debate among medical, professional, pro-life and disabilities groups regarding the ethics of treatment/nontreatment decisions affecting disabled newborns, including the role and responsibilities of States and the Federal Government, culminated in passage of the 1984 amendments to the Child Abuse Prevention and Treatment Act.

The amendments required State CPS units receiving formula grant funds under the Act to define baby doe situations as medical neglect, to establish procedures for responding to reports involving such infants, and to have liaisons designated in hospitals where babies are born or treated to insure the immediate referral of potential baby doe cases to CPS. Final implementing regulations were published in April 1985.

The amendments also required HHS to publish model guidelines encouraging hospitals to establish Infant Care Review Committees (ICRCs). Model guidelines were published in April 1985. The ICRCs are intended to educate hospital personnel and families of severely disabled infants, recommend policies and guidelines concerning the withholding of treatment, and review cases involving such infants.

This inspection was initiated at the request of the Surgeon General and the Administration for Children, Youth and Families, which administers the Act within HHS. The purpose of the inspection was to determine (1) how States are carrying out their baby doe responsibilities, and (2) how a group of hospitals with responsibility for acute infant care are structured and functioning to address potential baby doe situations.

The inspection was carried out in two phases. One phase consisted of a telephone survey of CPS units in all 50 States and the District of Columbia. A second phase involved visits to 10 large hospitals in 8 major cities around the country. Seven were children's hospitals identified with assistance from the Surgeon General.

This report, entitled "Survey of State Baby Doe Programs," describes the results of our survey of State CPS agencies. A companion report, entitled "Infant Care Review Committees under the Baby Doe Program," presents the findings of our hospital visits.

FINDINGS

STATE BABY DOE PROCEDURES ESTABLISHED

The Child Abuse Amendments of 1984 (P.L. 98-457) require that in order to qualify for formula grant funds under the Act, States must define baby doe situations as medical neglect, and establish procedures within the State Child Protective Services (CPS) system for responding to baby doe reports. State procedures were required to be in place by October 1985, and to include provisions for:

- designating individuals in hospitals to serve as the official liaison with CPS for all baby doe matters,
- prompt notification of CPS by these individuals of suspected baby doe cases, and
- authority for CPS to pursue legal remedies to prevent the inappropriate withholding of treatment from these infants.

Under the Act, States may apply for two types of grants: Basic Grants and Disabled Infant (Baby Doe) Grants. In Fiscal Year 1986, Basic Grants to States totalled $9 million, and $2.4 million was distributed nationwide in Baby Doe Grants. In order to qualify for a Baby Doe Grant, a State must first qualify for and receive a Basic Grant.

We surveyed CPS agencies in all 50 States and the District of Columbia. Forty-one jurisdictions received both Basic and Baby Doe Grants for Fiscal Year 1986. Seven other States applied for and received only Basic Grants, and three States (California, Indiana and Pennsylvania) did not apply for either Basic or Baby Doe Grants. Appendix A summarizes the types of activities undertaken by States with their Fiscal Year 1986 Baby Doe Grants.

Ten States reported they have passed special State laws or amended existing legislation to address baby doe situations. An eleventh State has developed a baby doe regulation which is expected to become law during 1987. The remaining States indicated that new legislation has not been necessary because their existing child abuse and neglect legislation covers baby doe situations.

Forty-eight States, including the seven which did not apply for Fiscal Year 1986 Baby Doe Grants, reported that State baby doe procedures have been established. Our survey found that all State procedures include provisions for prompt notification and CPS legal intervention, and nearly all have met the hospital liaison designation requirement in the Act.

Hospital Liaisons Designated in Most Hospitals

The following table depicts States' progress in designating hospital liaisons for prompt reporting of potential baby doe cases to CPS.

HOSPITAL LIAISONS DESIGNATED
(as of March 1987)

RESPONSE	STATES	
	NUMBER	PERCENT
All hospitals with NICUs or OBs	27*	53 %
More than two-thirds of hospitals with NICUs or OBs	13**	25
Less than two-thirds of hospitals with NICUs or OBs	6**	12
Don't Know	3	6
Liaisons not required (Nonparticipating States)	2	4
TOTAL	51	100 %

* Includes 6 States not receiving Federal baby doe funds.

** Includes 1 State not receiving Federal baby doe funds.

According to CPS respondents in 40 States, hospital liaisons have been designated in at least two-thirds of all hospitals where babies are born or treated. In six States, fewer than two-thirds of such hospitals have designated liaisons, while three States do not know the percentage of hospitals which have designated liaisons. Eight States not currently receiving baby doe funds are nevertheless following the Act's requirement to designate hospital liaisons.

Of those States providing information on frequency of updating their lists of hospital liaisons, 28 indicated their lists are updated annually, and 5 others update periodically or as needed.

Prompt Notification Systems Established

Our survey found that all States have systems in place to insure that CPS agencies can be notified immediately of any suspected instances of child abuse or neglect, including potential baby doe cases. These systems have been in operation for many years. Major features of prompt notification systems include:

- legal requirement for all professionals to report any suspected instance of child abuse or neglect to CPS;
- procedures for hospital liaisons to follow in reporting potential baby doe cases; and
- toll-free phone numbers.

About 80 percent of the States indicated that they have either statewide or local 24-hour toll-free phone numbers for receiving reports. While the remainder do not have toll-free numbers, they receive and respond to reports through local CPS offices during normal working hours, and have provisions for 24-hour phone coverage using a variety of arrangements. These include keeping local CPS switchboards open 24 hours and using the 911 emergency number or local police department as the first point of access.

Legal Intervention Authority Already Available

All States reported that CPS agencies have historically had legal authority, under State laws, to intervene when necessary to protect the well-being of abused or neglected children. Potential baby doe situations are covered under this authority. The CPS respondents indicated that if their investigation of a potential baby doe case determined that medically indicated treatment was being withheld, they would seek temporary custody of the infant and a court order to allow the needed treatment to be provided.

BABY DOE COMPARED WITH REGULAR CPS INVESTIGATIONS

We asked CPS respondents how their baby doe procedures differ from those used when investigating other reports of child abuse or neglect. Three major differences were cited consistently: immediate response, use of medical consultants and State level involvement.

1. Immediate Response

States report that due to the urgency and potentially life-threatening nature of baby doe situations, these reports are considered emergencies and are investigated immediately. In general, States require that the investigation begin with an immediate call to the hospital liaison where the infant is located to ascertain the basic facts in the case. In some States, a preliminary report is required within as little as 2 hours.

2. Use of Medical Consultants

All States report they have access to medical consultants to make medical determinations in baby doe cases. States use a variety of arrangements to insure immediate access to and availability of qualified medical consultants. Those mentioned most frequently were State level contracts with medical schools, children's hospitals or private pediatricians; and agreements with medical professionals employed by the State (frequently in State health or social services departments).

In a few States, local CPS offices are responsible for obtaining medical consultants. Several States have established multidisciplinary teams to investigate baby doe reports. These teams typically consist of a pediatrician or neonatologist, a social worker and a CPS worker, and could also include other medical specialists and legal expertise.

3. State Level Involvement

Abuse or neglect reports are routinely investigated at the local level. State CPS offices set policies, provide guidance and monitor the performance of local offices, but rarely conduct investigations. Because of the sensitivity of potential baby doe situations, many States have elevated the level at which these cases are handled. Nine States reported that the initial baby doe investigation would actually be conducted by State CPS staff. Several others require that the State office be notified immediately when a baby doe report is received; while the initial investigation would be handled locally, the State office would be kept informed and could step in to lead or participate in the case if needed.

ESTABLISHMENT OF HOSPITAL INFANT CARE REVIEW COMMITTEES

As required by the baby doe amendments, HHS published model guidelines to encourage hospitals with acute infant care responsibilities to establish infant care review committees (ICRCs). ICRCs are intended to educate hospital staff and families about baby doe situations, develop hospital policies and review potential baby doe cases.

We asked CPS units how many hospitals in their States have established ethics committees or ICRCs. State responses are shown below.

HOSPITALS WITH INFANT CARE REVIEW COMMITTEES

RESPONSE	STATES	
	NUMBER	PERCENT
All hospitals with OBs/NICUs	13	25%
More than half of hospitals with OBs/NICUs	2	4
Half or fewer hospitals with OBs/NICUs	22	43
All large hospitals with OBs/NICUs	4	8
Unknown/No response	10	20

Thirteen States (25 percent) reported that all hospitals with OBs or NICUs have ethics committees or ICRCs. The CPS respondents in 22 other States (43 percent) estimated that committees have been established in half or fewer such hospitals. Ten States (20 percent) did not provide any estimate. Additional detail on the number of hospitals with ICRCs established is provided at Appendix B.

State estimates are generally consistent with the findings of a national survey recently completed by the American Academy of Pediatrics (AAP). The AAP survey found that as of August 1986, about 52 percent of hospitals with over 1,500 births annually or an NICU were using committees to address ethical questions related to the care of severely disabled infants. An additional 8 percent were considering forming such a committee. [National Collaborative Survey of Infant Care Review Committees, AAP, March 1987].

We also asked State CPS offices what efforts they had made to encourage hospitals to establish ICRCs. Their responses are summarized in the following chart.

STATE EFFORTS TO ENCOURAGE ESTABLISHMENT OF INFANT CARE REVIEW COMMITTEES

RESPONSE	STATES	
	NUMBER	PERCENT
Some encouragement	23	45%
Little or no activity	14	27
Local responsibility	4	8
Function contracted out	3	6
No response	7	14

Nearly half of the States mentioned activities to encourage hospitals to establish ICRCs. Efforts range from letters to hospital administrators and CPS-sponsored seminars for hospital personnel to development of ICRC models and hosting conferences. About 25 percent of the States have done little or nothing in this area. In some States, most or all hospitals with NICUs have already established ICRCs or ethics committees, and no encouragement from CPS agencies is needed. Other States feel that such a decision rests with the hospital and it would be presumptuous of CPS to assume any role in that decision.

SIX BABY DOE CASES CONFIRMED SINCE OCTOBER 1985

We asked CPS agencies how many baby doe reports had been received in their States, both before and after October 1985, when the baby doe regulations took effect. As the following chart shows, the volume of reports received did not increase after October 1985.

BABY DOE REPORTS RECEIVED BY CPS AGENCIES*

	Pre-85	Post-85
Alabama	0	2
Alaska	0	1
Arizona	0	1
Arkansas	1	0
Connecticut	1	0
Florida	0	1
Georgia	4	1
Illinois	3	0
Indiana	1	0
Kansas	0	1
Kentucky	1	0
Maryland	0	1
Minnesota	0	1
New Hampshire	1	0
New Jersey	2	1
New York	0	2
North Carolina	1	0
North Dakota	1	0
Oklahoma	0	3
Oregon	2	0
Pennsylvania	1	0
Texas	0	1
Virginia	1	0
Washington	0	3
Wisconsin	1	0
Wyoming	1	0
TOTALS	22	19

* Does not include States which have never received a baby doe report or for which no information is available.

According to respondents, 22 baby doe reports were received in 15 States before October 1985, and 19 reports were received in 13 States since 1985. Twenty-four States have never received a baby doe report, and one State does not keep records at the State level.

Limited information was available on 13 of the 22 baby doe reports received before October 1985. The CPS intervened in 5 of the 13 cases and treatment decisions were changed in 4 instances. It is believed that two of the affected infants survive. In six cases, CPS review determined that the charges were unfounded, and two reports were not considered true baby doe cases. See Appendix C for additional detail on individual cases.

In 6 of the 19 reports received since October 1985, CPS investigation resulted in intervention by the agency to insure the proper application of the baby doe treatment guidelines. Four of these cases involved infants born with severe birth defects, one was a low-birthweight infant, and one baby was born healthy but suffered severe physical abuse. Treatment decisions were changed in all six cases, and five of the affected infants were living at the time of our inspection.

In nine cases, CPS investigation confirmed that the baby doe treatment guidelines were being applied appropriately and no further action was required. Six of the affected infants were severely disabled at birth, while three were born normal. Two of the three suffered child abuse while the third was injured in a fire.

Of the remaining four reports received by CPS agencies, two were determined not to be true baby doe cases, and no information is available for two reports.

Additional information on the 19 baby doe reports received since October 1985 is provided at Appendix D.

STATE COMMENTS ON BABY DOE RESPONSIBILITIES AND FUNDING

In Fiscal Year 1986, nearly $11.5 million in Federal funds was distributed to States in the form of Basic Grants and Baby Doe formula grants. Over $2.4 million (21 percent) of this total was for Baby Doe Grants.

We asked CPS agencies to comment on the appropriateness of their baby doe responsibilities and the need for continued Federal Baby Doe Grants. Some States made more than one comment, while others chose not to comment at all. The range of opinions expressed by respondents are highlighted below.

CPS COMMENTS	STATES	
	NUMBER	PERCENT
A. CPS Responsibility		
It is appropriate for CPS to handle baby doe cases at State level.	28	55%
Because of medical and ethical issues involved, CPS responsibility for baby doe cases is not appropriate.	11	22
B. Federal Funding		
Baby doe funds are useful, but State would continue to carry out program without special funding.	13	25
Baby doe funds could be put to better use on general child protective programs, medical neglect or other priorities identified by States.	12	24
State could not operate baby doe program without special funds.	11	22
Federal set-aside funds were useful initially, but are no longer needed.	8	16
Baby doe problem is too small to warrant special Federal funds or attention.	5	10

While over half of the respondents stated that CPS is the appropriate State agency to handle baby doe reports, nearly one-quarter felt that baby doe cases involve medical and ethical issues which should be dealt with in hospitals between parents and medical professionals.

Opinions on the continued need for special Federal funding differ as well. About one-quarter of the States indicated that their baby doe programs would suffer without special Federal funding. Another quarter felt that States should have the discretion to determine how to spend their available Federal funds. States could continue to devote these resources to baby doe programs exclusively, but would also have the flexibility to use their grants for medical neglect in general or other priorities.

OBSERVATIONS

The Federal baby doe amendments appear to have been successful in focusing CPS attention on the needs of severely disabled infants with life-threatening conditions. The CPS units in 48 States, including 7 which did not apply for Fiscal Year 1986 Baby Doe Grants, have established procedures to respond to reports involving such infants. All procedures include the provisions required in the law for hospital liaisons, prompt notification and legal intervention authority.

In addition, CPS units have generally fulfilled their responsibilities to have liaisons designated in hospitals with NICUs or OBs, and to provide information and training to these individuals on their role in reporting potential baby doe cases to CPS. The CPS units in some States have also played a role in encouraging affected hospitals to establish ICRCs or ethics committees.

It is not clear what impact the Federal legislation and increased State responsibility have had on the incidence or handling of baby doe reports. There has been no significant increase in the volume of reports received after October 1985, and most States reported that they handled cases essentially the same way even before the Federal law was passed. Prior to the baby doe legislation, States used existing child abuse and neglect procedures to respond to reports of medical neglect, including baby doe reports. Such cases were treated as emergencies, and medical expertise was sought as needed.

In view of the heightened awareness and attention to baby doe, many States feel that the special Federal baby doe set-aside funding is no longer needed. They believe that States should have the discretion to use these funds for child abuse and neglect priorities identified at the State level, including baby doe if needed. In contrast, other States feel that they would be unable to operate their baby doe programs without the set-aside funding.

Appendix 3

INFANT CARE REVIEW COMMITTEES

UNDER

THE BABY DOE PROGRAM

RICHARD P. KUSSEROW
INSPECTOR GENERAL

SEPTEMBER 1987

OAI-03-87-00042

[Executive Summary and Appendices omitted.]

INTRODUCTION

The term baby doe refers to a severely disabled infant with a life-threatening condition who is denied appropriate medical treatment. Two highly publicized court cases called national attention to baby doe in the early 1980s, and led to Federal legislation to protect the rights of such infants.

In the first case, an infant known as Baby Doe was born with Down's syndrome and a surgically correctable blockage of the esophagus. The baby's parents and doctor agreed that surgery should not be performed and that food and water should be withheld from him. The hospital sought a court order to permit surgery, but the court upheld the parents' decision, and the State supreme court refused to disturb the lower court's ruling. Baby Doe died before the case could be filed in the U.S. Supreme Court.

The second case involved an infant known as Baby Jane Doe, who was born with multiple neural tube defects, including spina bifida (an open lesion on the spine), microcephaly (an abnormally small head), and hydrocephaly (an accumulation of fluid on the brain). The parents approved medical treatment to reduce the chance of infection, but refused surgery to close the spinal lesion and drain excess fluid from the baby's brain. The parents' decision was later upheld by the State courts. It is not known what became of Baby Jane Doe.

In March 1983, the Department of Health and Human Services (HHS) published an interim final rule stating that section 504 of the Rehabilitation Act of 1973 applied to handicapped infants and establishing a Federal hotline for reports of failure to feed and care for such infants. One month later, the interim final rule was struck down in U.S. District Court. The Department published revised proposed regulations in July 1983 and final regulations in January 1984. These final regulations were struck down in U.S. District Court in June 1984.

The two baby doe cases and the subsequent debate among medical, professional, pro-life and disabilities groups regarding the ethics of treatment/nontreatment decisions affecting disabled newborns, including the role and responsibilities of States and the Federal Government, culminated in passage of the 1984 amendments to the Child Abuse Prevention and Treatment Act.

The amendments required HHS to publish model guidelines encouraging hospitals to establish Infant Care Review Committees (ICRCs). Model guidelines were published in April 1985. The ICRCs are intended to educate hospital personnel and families of severely disabled infants, recommend policies and guidelines concerning the withholding of treatment, and review cases involving such infants.

The HHS model guidelines are advisory only. There is no Federal requirement for hospitals to establish ICRCs or to adhere to any aspect of the guidelines. Nevertheless, a national survey by the American Academy of Pediatrics (AAP) found that as of August 1986, about 52 percent of hospitals with over 1,500 births annually or a neonatal intensive care unit (NICU) were using committees to address ethical questions related to the care of severely disabled infants. An additional 8 percent were considering forming such a committee. The AAP study also found that the majority of committees already established generally conformed to the structure, procedures and functions outlined in the HHS model guidelines [National Collaborative Survey of Infant Care Review Committees, AAP, March 1987].

The 1984 amendments also required State CPS units receiving formula grant funds under the Act to define baby doe situations as medical neglect, to establish procedures for responding to reports involving such infants, and to have liaisons designated in hospitals where babies are born or treated to insure the immediate referral of potential baby doe cases to CPS.

This inspection was initiated at the request of the Surgeon General and the Administration for Children, Youth and Families, which administers the Act within HHS. The purpose of the inspection was to determine (1) how a group of hospitals with responsibility for acute infant care are structured and functioning in addressing potential baby doe situations, and (2) how States are carrying out their baby doe responsibilities.

The inspection was carried out in two phases. One phase consisted of visits to ethics committees in 10 large hospitals in 8 major cities around the country. Seven were children's hospitals identified with assistance from the Surgeon General. A second phase involved a telephone survey of CPS units in all 50 States and the District of Columbia.

This report, entitled "Infant Care Review Committees under the Baby Doe Program," presents the findings of our hospital visits. A companion report, entitled "Survey of State Baby Doe Programs," describes the results of our survey of State CPS agencies.

FINDINGS

HOSPITAL ETHICS COMMITTEES ARE ESTABLISHED AND FUNCTIONING

We visited 10 hospitals in 8 major cities around the country. Selection was based in part on the fact that they were known to have committees which review problematic cases. The hospitals visited included seven children's hospitals, one large county hospital, one large general hospital and one medical center affiliated with four other hospitals in the same metropolitan area. The children's hospitals visited have NICUs. The other three hospitals have large maternity wards as well as NICUs.

While committees have been established at all 10 hospitals, most are not ICRCs focusing exclusively on baby doe cases. Nine are ethics committees which review the full range of problematic cases encountered in the hospital, including baby doe cases. One of these ethics committees has established an ICRC as a subcommittee. The tenth hospital has a separate infant bioethical review committee.

In nine hospitals, committees were established and functioning prior to publication of the HHS model guidelines. Several have been in place for more than 10 years. One hospital established its committee after the guidelines were published. Historically, this hospital had handled ethical treatment issues on an ad hoc basis.

Committee Membership

The HHS model guidelines recommended that committees be established as multidisciplinary teams with core members and advisors or supplemental members. The suggested core members include: practicing physician (pediatrician, neonatologist or pediatric surgeon), practicing nurse, social worker, hospital administrator, disability group representative and member of the facility's medical staff who serves as the chairperson. A member of the clergy, an attorney or judge, and other medical specialties were suggested as advisors or supplemental members.

We found that while committee membership varies, all include pediatricians and/or neonatologists, social workers, nurses and representatives from hospital administration. Legal expertise is always available, although not necessarily in an official membership capacity. Most committees also include members of the clergy, ethicists, disability group representatives and patient representatives or advocates.

The baby doe amendments require State CPS units to have liaisons designated in hospitals where babies are born or treated to assure the prompt reporting of baby doe cases to CPS. The model guidelines suggest that the hospital liaison be a committee member. Four committees reported that the hospital liaison is a member. Three of the remaining committees are in States which do not participate in the Baby Doe program and do not require the appointment of hospital liaisons. Committees at all hospitals visited reported they are familiar with CPS professional reporting requirements for all instances of child abuse and neglect, including baby doe. They feel that cases will be reported to CPS promptly whether or not an officially designated liaison sits on the committee.

Meeting Schedule

The HHS model guidelines suggest that committees meet regularly and also as needed to review specific cases. Committees at all hospitals visited meet as needed to review problematic cases prospectively. Eight committees also meet on a regular basis. Five meet monthly, two meet quarterly and one meets twice a month. Most meetings do not deal with baby doe issues or individual baby doe cases, but are devoted to policy development, education, or review of problematic cases involving older patients.

COMMITTEE RESPONSIBILITIES VARY

The HHS model guidelines suggest three major functions for hospital ICRCs: (1) to offer counsel and review in individual cases, (2) to recommend institutional policies and guidelines, and (3) to educate hospital personnel and families. The committees in our sample vary, both in the extent to which they perform these functions and in the importance attached to them.

1. Reviewing Individual Cases

Prospective case review is done by all committees visited, and is considered their most important function. Committee recommendations on individual cases are advisory only, rather than binding on the involved parties. Committee members pointed out that differences of opinion between treating physicians, parents and the committee can usually be resolved through an informal discussion process. If this is not possible, the hospital refers the case to CPS for investigation and possible legal action.

One committee indicated that it also reviews selected cases retrospectively, and a second plans to start soon. Several committees mentioned that patient deaths are reviewed retrospectively by other committees as part of the hospital's ongoing quality assurance process.

2. Recommending Institutional Policies

All committees visited recognized that the development of institutional policies, ranging from the types of cases which should be considered by the committee to guidelines for addressing particular types of cases, as an appropriate function for the ethics committee. The extent to which such policies have actually been developed varies from hospital to hospital. While most committees have adopted at least rudimentary written policies, two committees indicated that they are just beginning to address their policy development responsibilities.

Several respondents noted that the ethics of medical treatment decisions is constantly being rethought, reviewed and revised. This is due in part to continuing advances in medical technology. We were told by one neonatologist, for example, that recent advances now enable 80 percent of infants weighing as little as two pounds at birth to survive. This was not possible prior to the early 1980s. Low birth weight infants are often born with severe medical problems, some of which may result in permanent disabilities despite vigorous medical intervention.

3. Educating Staff and Families

Three committees mentioned they hold regular educational sessions for interested hospital staff where case information is shared and the ethics of particular treatment options and decisions are discussed. These sessions cover the full range of seriously ill patients treated at the hospital, and are not limited to potential baby doe situations.

Committees at all 10 hospitals indicated that their existence and role as advisor on problematic cases are well known to hospital staff, particularly those most likely to come into contact with disabled infants. Neonatologists, NICU nurses, hospital social workers, and members of the administrative staff know of the ethics committees and their case review role. Because of this general knowledge, educating hospital personnel is not considered a major need by ethics committees at the hospitals we visited.

Educating families of seriously ill infants is seen as the responsibility of other hospital staff, usually the patient representative or social work staff, rather than the ethics committee. Typical activities of these staff are to inform families of the existence and functions of the ethics committee, assist families in requesting ethics committee review of their infant's medical care when appropriate, and provide information and assistance in obtaining needed support services in the community following patient discharge.

BASIC CASE REVIEW CRITERIA ARE COMPARABLE

1. Prospective Case Review

The HHS model guidelines suggest that emergency ICRC meetings be called to review cases prospectively under the following conditions:

- disagreement between family and physician about the proper course of treatment;
- disagreement between hospital staff members; and
- when a preliminary decision has been made to withhold or withdraw life-sustaining treatment.

All committees indicated they review cases involving disagreement between principal parties in the case (treating physician, parents, other hospital staff). They also review cases where the treating physician is uncertain about the proper course of treatment. In such instances, the committees serve as a consultative body to advise the treating physician on the most appropriate course of treatment.

Committee practices differ in handling cases where a preliminary decision has been made to withhold or withdraw life-sustaining treatment. One committee requires review of any case in which cessation of life-sustaining treatment is proposed, unless the infant is clearly terminal and continued medical intervention would serve no beneficial purpose. In these instances, a small subcommittee reviews the case to assure that reasonable medical guidelines are being followed. In a second hospital, if the principal physician recommends cessation of treatment, two colleagues must agree before treatment can be withheld. Eight committees reported that they do review cases brought to their attention involving the possible withholding or withdrawal of life-sustaining treatment. Prospective review of such cases is not, however, mandatory.

2. Retrospective Case Review

The HHS model guidelines recommend that ICRCs review records retrospectively in cases involving the withholding or termination of medical treatment, except for cases which were reviewed prospectively. Findings which deviate from hospital policy should be reported to appropriate hospital personnel and hospital policies revised, if necessary.

One of the 10 ethics committees visited reviews cases retrospectively on a selective basis. The hospital itself conducts monthly mortality conferences to review every patient death from a medical point of view. If the death is based on withholding or withdrawal of medical treatment, it is referred to the ethics committee for further review. Review results are sometimes used for educational purposes within the hospital.

A second ethics committee indicated that it plans to begin retrospective case review in the near future. Several committees mentioned that some cases are reviewed retrospectively by other committees as part of ongoing quality assurance activities within their respective hospitals.

COMMITTEE CASE REVIEW EXPERIENCE

Among them, the hospital committees visited estimate they have reviewed between 20 and 36 potential baby doe cases since the Federal regulations went into effect in October 1985. Most committees do not keep individual case records and were unable to provide precise information on the numbers of cases reviewed.

Advising physicians and families on the most appropriate course of treatment for severely disabled infants with life-threatening conditions is a responsibility which is taken seriously by hospital ethics committees. Members are mindful of their responsibilities and strive to apply the baby doe legal requirements while considering the medical, ethical and moral issues associated with each individual situation.

Parental consent is required in order for a hospital to perform surgery or withhold or withdraw treatment. Committees indicated that parents of some severely disabled infants initially refuse consent for surgery or life-sustaining treatment, while others demand that treatment be continued even when the treating physicians and ethics committees agree that continued treatment would be futile and painful, and would merely prolong the infant's dying.

Committee recommendations are advisory only, rather than binding on the affected parties. Committee members noted, however, that most situations involving initial differences of opinion have been resolved in accordance with baby doe requirements, and few cases have been reported to CPS.

Eight hospitals have not reported any cases to CPS. They indicated that all cases reviewed have been resolved informally. If a case could not be resolved within the hospital setting, they indicated that they would seek CPS intervention.

Two hospitals have made three reports. In these three cases, parents refused consent for life-saving treatment or surgery recommended by the hospital. CPS intervention led to continuation of treatment. Two of the affected infants were living at the time of our fieldwork.

While hospital committees declined to discuss the details of individual cases reviewed, several respondents commented generally on the types of cases most often referred for review:

- The types of cases most frequently reviewed by committees involve low birthweight (less than 2 pounds), extensive internal bleeding associated with premature birth, and asphyxiation during the birth process. These infants have little chance for survival even with vigorous, and often painful, medical intervention.

- Committees also review cases involving multiple and severe birth defects, including hydrocephaly (fluid on the brain), anencephaly (most of the brain missing), microcephaly or macrocephaly (abnormally small or large head), deformities of the face and extremities, blocked esophagus and little or no large intestine. Such conditions usually occur in some combination and are frequently associated with severe or profound mental retardation. Some conditions cannot be corrected. While it is surgically possible to open a blocked esophagus, for example, there is no treatment for anencephaly. Committee members indicated that the long-term prognosis for infants born with combinations of conditions such as those described above is uncertain.

- The two conditions which gave rise to the baby doe amendments, Down's syndrome and spina bifida, are generally not problematic for the hospitals visited in terms of whether or not to provide treatment. Committee members indicated that infants with these two diagnoses have been routinely treated in their hospitals for 15-20 years.

- Even in an instance when an infant is imminently dying and the decision is made to withdraw or withhold treatment, the infant continues to receive nutrition and hydration and is made as comfortable as possible during the dying process.

DESCRIPTION OF AN ETHICS COMMITTEE

This section describes the structure and functions of a series of interlocking Infant Bioethical Review Committees established in February 1984 in four affiliated hospitals which make up the Albert Einstein College of Medicine and the Montefiore Medical Center in the Bronx, New York. This group of hospitals was visited as part of the inspection. Its committees are generally structured and functioning in conformance with the HHS model guidelines, and may serve as a useful reference for hospitals considering the establishment of similar committees.

Since four institutions are involved, a decision was made to have separate but interlocking committees. A core group of experts serve on all four committees, and additional members have been appointed to each hospital's committee. The core group includes: a neonatologist who chairs all four committees; three other pediatricians with expertise in neonatology, disabilities and rehabilitative medicine; a lawyer working in a medical setting; and two bioethicists. Each institution has appointed nursing, social work, administrative and community representatives for its own committee. An attorney in one hospital's general counsel's office serves as a nonvoting consultant to each committee.

The core group and all members from the four hospitals meet monthly to develop general guidelines and procedures and review cases retrospectively. Ad hoc consultants may attend meetings upon invitation of the chairman, but may not vote. Minutes are kept. Many decisions are reached through consensus. When a vote is required, however, a two-thirds majority of members present is required for passage.

The committees have agreed to a set of principles which serve as the basis for making decisions involving critically ill infants. These principles recognize the intrinsic worth of the infant which entitle it to all appropriate care determined to be in its best interests, irrespective of its disability or handicap. Caregivers are obligated to provide such care. The principles recognize that it is sometimes uncertain what medical treatment is in the best interests of a particular infant. Parents are responsible for making decisions for their infant, unless they choose a course of action that is clearly against the infant's best interests. Withholding or withdrawing treatment may be considered when it is deemed futile and would merely prolong the dying process or when the medical treatment imposes a burden which lacks compensating benefits for the infant. If such a decision is made, the infant and the family are cared for in a supportive and dignified manner.

The committees review cases involving infants up to 2 years of age. Cases are reviewed prospectively as well as retrospectively.

Prospective Review -- Each committee convenes on an emergency basis at the request of the Chairman for prospective case review. Mandatory review is required when:

- o withdrawal of life-sustaining treatment is being proposed for a patient who is not imminently dying; and
- o there is disagreement between or among health care providers and families concerning withdrawing or withholding life-sustaining treatment.

Parents are informed when their case is being reviewed, but parental consent for review is not required. Caregivers, parents, clergy and other relevant parties are encouraged to meet with the committee or attend portions of the meeting. They may not be present during final deliberations and voting. Members with direct responsibility for the infant's care do not vote.

Committee recommendations are shared with the involved parties immediately after the meeting. If the parents and treating physician agree with the committee's recommendation, no further committee action is required. If, after extensive discussion, differences of opinion cannot be resolved, the committee recommends that the hospital seek intervention by the Child Protective Service Agency for action to permit appropriate treatment or the withdrawal or withholding of life support.

Full committee review is not required for cases in which no further treatment is being considered because the infant is clearly terminal and continued intervention would serve no beneficial purpose. However, a small subcommittee does review such cases to insure that they adhere to reasonable medical guidelines and that the family has been properly consulted. These cases are reviewed retrospectively at the next monthly meeting.

Retrospective Review -- The full committee reviews deaths resulting from the withholding or withdrawing of medical treatment. Retrospective reviews are held for information and education of the committee, as well as to generate guidelines which will be helpful in reviewing future cases.

Note: This description is based on the following references:

1. Fleischman, Alan R., M.D., "Bioethical Review Committees in Perinatology," *Clinics in Perinatology*, Volume 14, No. 2, June 1987.

2. Fleischman, Alan R., M.D., "An Infant Bioethical Review Committee in an Urban Medical Center," *Hastings Center Report*, June 1986.

ETHICS COMMITTEE COMMENTS ON IMPACT OF BABY DOE PROGRAM

We asked hospital ethics committees to comment upon the impact of the baby doe legislation and the effectiveness of the current system. The sample of comments provided below, mostly from physician committee members, illustrate the range of opinions expressed.

- "The baby doe legislation focused our attention on this issue. We are now more aware of ethics committees and their functions, as well as the requirement to report suspected cases to CPS."
- "While Federal involvement has raised consciousness about baby doe, these problems involve medical and ethical issues which do not belong in CPS. What is needed is increased sharing of information among involved parties, not regulation by CPS. I find it philosophically, emotionally and professionally repugnant to involve CPS in the decisionmaking process."
- "The current system is effective. CPS provides the support and legal backing which enable us to provide the most appropriate medical care. The Federal law has heightened our awareness of baby doe issues."
- "When in doubt, ethics committees and physicians err in the direction of providing treatment, even when the infant's chances of survival are extremely slim."
- "Fear of malpractice lawsuits has caused many hospitals and physicians to continue treatment for infants who have virtually no chance for survival. The treatment is often painful and only prolongs the infant's dying."
- "Severely disabled infants born in community and maternity hospitals are routinely transferred to children's hospitals, even when the infant is clearly dying. The birth hospitals fear being accused of failing to do everything possible to save the infant."
- "Medical technology may be doing a disservice by delaying a death that is imminent. Respirators can now keep nonviable babies alive temporarily, only delaying their inevitable deaths for a month or two."
- "The real unmet need is for day care facilities and other supportive services specifically designed for these babies who may not receive the special care and attention they require once they leave the hospital."
- "It is morally repugnant to give treatment that is painful to the child and clearly has no useful purpose."

OBSERVATIONS

The inspection found that while nearly all hospitals visited had established ethics committees prior to passage of the baby doe legislation, most respondents feel that the legislation and model guidelines have helped to focus their attention on potential baby doe situations. While the HHS model guidelines are advisory rather than mandatory, the majority of hospitals with large maternity wards and/or NICUs do have ethics committees which review and advise on neonatal cases, including the treatment of severely disabled infants. All 10 of the committees visited during the inspection report they are structured and functioning substantially in conformance with the HHS model guidelines.

All committees visited recognize their responsibilities to develop hospital policies addressing the treatment of severely disabled infants and to review individual cases on a prospective basis. While specific case review criteria vary somewhat, all committees are available to meet on an emergency basis to consider and recommend the most appropriate course of action in treating these infants. Applying the baby doe provisions in the law, committees are usually able to arrive at consensus regarding the most appropriate course of treatment. Most disagreements are resolved informally, but when necessary, hospitals do not hesitate to seek CPS intervention.

Disagreement between the involved parties appears to be the major criterion for committee review; while committees do review cases brought to their attention which involve the possible withholding or withdrawal of life-sustaining treatment, prospective review of such cases is not mandatory in 8 of the 10 hospitals visited.

The hospitals visited do not believe there is a need for increased publicity or attention to baby doe issues at the Federal level. However, several respondents mentioned a continuing unmet need for specialized day care, adoption assistance and related community-based supportive services to meet the needs of these special infants following hospital discharge. The Department may wish to consider alternative means to increase the availability of such services at the local level.

Appendix 4

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Betty A. Lowe, M.D.
Little Rock, Arkansas

George D. Comerci, M.D.
Tucson, Arizona

Martin Gershman, M.D.
San Francisco, California

May 1, 1989

William B. Allen
Commission on Civil Rights
1121 Vermont Avenue, N.W.
Room 800
Washington, D.C. 20425

Dear Mr. Allen:

The AAP regrets the process and the substance of the Commission report. There was very little opportunity for groups and/or individuals to explain the current decision-making process in intensive care newborn nurseries. The Commission's process did not allow for a thorough hearing of the issues.

The report takes an extreme position rather than a balanced view of the complex issues involved in caring for critically ill newborns. Its tone throughout is that of a conclusion in search of arguments rather than a reasoned response to the difficult questions involved.

The report dwells on events that occured in the decade prior to the historic compromise which culminated in the 1984 amendments to the federal Child Abuse Act. It describes case studies and attitudes from an earlier era as if they had some relationship to the present. A number of groups using a variety of monitoring mechanisms have observed that infants with Down Syndrome, spina bifida and other anomalies are now receiving appropriate care.

The Commission seriously understates the importance of the dramatic growth of hospital ethics committees (also called infant care review committees) since 1985. This transformation in the way decisions are made occurred on a voluntary basis with no federal or state requirements. They were a result of the conviction of the Academy and other groups that multi-disciplinary review would facilitate decision making in difficult cases. Those who predicted that hospitals and physicians would not form such committees, or that committees would not become involved in decisions, or that committees would accept decisions without discussion or dissent were wrong. Rather than acknowledge this success, the Commission simply ignores it.

The Commission advocates an extreme view of the Child Abuse Amendments and related regulations, one that would require maintenance of biologic existence in virtually all infants other than the comatose and the dying. It fails to acknowledge the carefully crafted language which reflected a rejection of that view by many groups and individuals who care for and about infants. It resurrects a position which would not take into account an infant's interests, nor allow any person or group or court to make any judgements about the care of a sick or suffering infant. This view is not only contrary to the spirit and language of the law and regulations, but contrary to a clear trend in American law and opinion which demands that handicapped and critically ill infants, like all patients, be entitled to have decisions regarding life-sustaining treatment made in their best interest.

The Commission advocates a renewal of intrusion of federal authority into complex decision making at the bedside. This view is contrary to federal appellate and US Supreme Court opinion, as well as public opinion. It resurrects an approach which was implemented in the infamous "Baby Doe hotline" and "Baby Doe squads" that failed to achieve its objective. It was an approach which failed to identify serious errors at a time when they were common, and which falsely labelled excellent clinical care as neglect, driving infants and parents fearfully out of intensive care units to avoid onrushing and intrusive federal authorities.

Furthermore, the most recent Inspector General's survey of Baby Doe programs release just last year showed that the problem of undertreatment is being appropriately addressed. In commenting on that report, Surgeon General Koop said that, "It is reassuring to learn...that each state has accepted its responsibility and fully implemented the 1984 amendments to the Child Abuse Prevention and Treatment Act." Dr. Koop went on to say that the report indicates that the "guidelines and procedures are working appropriately."

All evidence points to the fact that the law is working. The Academy continues to support the use of infant care review committees as an important mechanism to assist physicians and parent in making these difficult decisions. The Academy also continues to educate and train our pediatrician members about the use of committees and other methods of aiding children with disabilities and their parents.

Sincerely,

Donald W. Schiff

Donald W. Schiff, M.D.
President

Statement of Commissioner Robert A. Destro

It should not have been this difficult. The point, after all, is a fairly simple one: that it is both illegal and immoral to deny necessary medical care to any child, especially one with a disability. That it has taken the Commission nearly 5 years to complete its report and recommendations bears witness to the formidable political and practical hurdles which had to be overcome. But overcome they were, and as the Chairman of the subcommittee responsible for producing and editing the several drafts of the report and recommendations, I am both pleased and grateful to the Commission and its staff for the hard work, late nights, and commitment to seeing this project through to completion.* I write separately to summarize some of the practical and political issues the Commission had to overcome in the course of its deliberations, and to suggest a wider context in which this report and its recommendations should be viewed.

Defining the Problem: Discrimination, Medical Ethics and Family Privacy

The primary conceptual and political problem faced by the Commission has been to distinguish among those issues which are correctly within the realm of antidiscrimination and child neglect laws, those which are properly matters of medical judgment or ethics, and those which are matters of parental choice. Though the dividing line which separates these spheres is far from clear, it is quite real; and the need to make careful distinctions is critical.

It goes without saying, for example, that neither child abuse and neglect nor discrimination on the basis of disability are "private" matters. That a parent's decision to neglect a child's medical needs is either influenced by or acquiesced in by a physician likewise does not transmute the issue of neglect into one of medical judgment, ethics, or confidentiality. The proper (and limited) concern of law is the prevention and punishment of antisocial activity. Medical neglect (that is, the denial of medically indicated treatment) of the physically or mentally disabled is, by definition, antisocial, and the proper concern of the law.

The question addressed in this report is simply stated: is it permissible under either State or Federal law to deny necessary medical care to any person on the grounds that a disability or other immutable characteristic such as race, sex or ethnicity makes that person an unfit subject for treatment? Phrased another way, the question is: whether medically indicated (i.e. necessary) treatment for a given condition becomes any less "necessary" when the patient has a disability?

That this is the issue cannot be doubted. The physician who treated Bloomington Indiana's Baby

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* Special thanks go to my friend and colleague Commissioner Esther Gonzales-Arroyo Buckley, for her work as the other member of the subcommittee, and to my former confidential assistant, Deborah Lawrence (now of Fort Wayne, Indiana), whose hard work and persistence were largely responsible for the completion of the hearing record. It is also appropriate to recognize the contribution to the finished product made by the Commission's late Chairman, and the original chair of the subcommittee, Clarence M. Pendleton, Jr. Though Penny and I had many a late-night disagreement over the what we might find in the course of additional hearings, he supported additional factfinding. In addition, he also resisted internal and external political attempts to kill the project outright.

Doe[1] admitted on the record of the Commission's June 1986 hearing that he had told the baby's parents that "[they] must realize that if the child has the surgery, and if the surgery is successful, that this child will still be a Down's syndrome child with all that that implies." Since, in his view, "the parents were pretty well-acquainted and had a good knowledge of what this implied[, he] said to them [that] 'There is the alternative of doing nothing, in which case the child will survive a few days and will die.'"[2]

The baby was not dead, he was not dying, and the indicated surgery was neither futile nor medically contraindicated. The "problem" was that the little boy had Downs' Syndrome. Had he been "normal" (i.e. not disabled) not a court in this country would have stood by as he died of starvation and dehydration. Nonetheless, they did—up to and including the Supreme Courts of Indiana and the United States.

Such attitudes and behaviors cannot be tolerated in a civilized society. They are a cancer growing at its very heart. It makes no difference whether the decision is that of the parents, a physician, an "ethicist," an ethics committee, a judge, or a combination of all of them; for whatever the euphemism chosen to describe what is going on in the limited category of cases dealt with in this report, the real names of the practices are eugenic discrimination and euthanasia.

To subsume the question entirely into the realm of medical ethics, as the statement of Chairman William B. Allen[3] does, is to unwittingly fall into the trap suggested by Leo Alexander, an observer at the trials of the Nazi war criminals at Nuremburg, who wrote in 1949 that:

> The beginnings [of the Nazi terror] at first were merely a subtle shift in emphasis in the basic attitude of the physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the nonrehabilitable sick.
>
> It is, therefore, this subtle shift in attitude that one must thoroughly investigate.[4]

Robert Jay Lifton's 1986 book, The Nazi Doctors,[5] described the process decried by Alexander as the gradual "medicalization" of eugenic killing and neglect. The record and the literature reviewed in this report confirm that the same phenomenon is at work here.

This is why many, if not most, of the arguments raised in opposition to this report are either ill-informed or disingenuous. Chairman Allen, for example, argued during the final debate on the report that it lacks "numbers [concerning] what is actually transpiring in the country. That is a relatively simple calculation to effectuate."[6] Given the difficulty of the legal, medical, and ethical issues, as well as the potentially great legal and financial risks associated with reporting behavior which is arguably illegal under state and federal law, it is incomprehensible that anyone knowledgeable on the subject could allege that the incidence of discriminatory denial of treatment "is a relatively simple calculation to effectuate." The "hard" evidence is all to the contrary.

When the government sought to encourage reporting by posting an informational notice in hospitals for the benefit of families and medical personnel similar to those required by labor and other civil rights laws, the courts enjoined the requirement. Medical personnel have been fired or disciplined for reporting denial of treatment cases to child welfare personnel. The Office for Civil Rights of the Department of Health and Human Services was opposed to investigating alleged cases of medical care neglect of infants with disabilities. The investigatory ardor of the Civil Rights Division of the Department of Justice cooled noticeably after the government lost the ***Bowen v. American Hospital***

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[1] *In re* Infant Doe, No. GU8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.* State of Indiana on Relation of Infant Doe by Guardian, No. 482 S139 (Ind. S. Ct, May 27, 1982), No. 482 S.140 (Ind. S. Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

[2] *Hearing Before the United States Commission on Civil Rights: Protection of Handicapped Newborns* 224-25, 228-29 (1986) (vol. II).

[3] Chairman William B. Allen, "A Dissenting View on the Report *Medical Discrimination Against Children with Disabilities.*"

[4] Alexander, *Medical Science Under Dictatorship*, 241 New Eng. J. Med. 39, 41 & n.17 (1949) (quoting J. Bernal, The Social Function of Science 44 (6th ed. 1946)).

[5] Lifton, The Nazi Doctors: Medical Killing and the Psychology of Genocide (1986).

[6] United States Commission on Civil Rights, Transcript of Meeting of Jan. 9, 1989 at 49 (remarks of Chairman Allen).

Association[7] case, even though the majority relied on alleged defects in the investigatory record to strike the so-called "Baby Doe" rules.

Thus, it is not surprising that the Commission's Specific Findings Three, Four and Five Regarding the Child Abuse Amendments of 1984 raise serious questions concerning the legitimacy of internal self-regulation by hospital ethics committees as well as the effectiveness of past and future oversight by the Office for Civil Rights of the Department of Health and Human Services. Discrimination against the disabled in the medical setting has been so thoroughly "medicalized" by physicians and ethicists, and "privatized" by courts and commentators that the Chairman's argument that the number of cases "is a relatively simple calculation to effectuate" cannot be taken seriously.

In fact, the only real way to get the "numbers" is retrospectively: after the treatment has been denied. Specific Recommendation Eight Regarding the Child Abuse Amendments of 1984 places the Commission on record as urging "retrospective reviews of the medical records of those with disabilities who die in [a] State" by the local Protection and Advocacy [P&A] System.

In my view, however, the focus on "how many" such cases is simply wrong; for it ignores the obvious. Whenever noted physicians, ethicists, and researchers publish articles in major academic and professional journals reporting discriminatory behavior against disabled persons as if there were nothing wrong with it, there are at least two serious problems which make the number of cases almost beside the point.

First, the boldness with which the discrimination is reported conveys the attitude that those involved see no problem with their behavior. Second, and more relevant to the Commission's task, the fact that courts have, on occasion and in the face of great public scrutiny, authorized admitted medical neglect of persons with disabilities[8] means that discriminatory attitudes about the "quality" of their lives are shared by those whose obligation it is to enforce our civil rights laws.

Complicating the matter further, some courts and legal commentators have argued that, due to their difficulty and intensely personal nature of denial of treatment cases, they are (or should be) considered as matters within the zone of constitutionally protected family privacy. To "privatize" the issue is, of course, to argue that it is not only permissible, but also outside the legitimate purview of the law. In my view it is equally wrong to take this approach as it is to accept the arguments of those who would "medicalize" the problem. The result is the same: only the method is different. The Commission quite rightly, and without recorded dissent, rejected both.[9]

Placing the Report in Context

The important facts contained in most reports, including his one, are often the most obvious ones. Though the Commission's report makes it quite clear that discriminatory denial of necessary treatment to newborns with disabilities was the subject of this study; those opposed to its conclusions have focused instead on overtreatment of patients for whom it may be either unless or harmful, especially neonates (very premature newborn infants).[10] Characterized in this manner, the problem becomes technology gone wild, not discrimination. Ethicists and medical experts can then safely be cast as the victims of an ill-informed, narrow-minded "life-at-any-cost" ethic (termed "vitalism") which does not take into account the dignity of the individual forced to live a life in which there is no hope.

It is a powerful—and dangerously irrelevant—argument. "Overtreatment" of anyone is, by definition, both "unnecessary" and unethical. Physicians and ethicists cannot be permitted to hide behind the family when the issue is overtreatment, any more than they should be able to do so when discrimination is the basis for failure to treat. Overtreatment was never the focus of this study, notwithstanding the attempt to make it so. The focus is—and should always remain—on the legitimacy of individual and collective decision-making. If the decision is a legitimate medical one, it is not for the law to second-guess. If it is based on social or eugenic factors, we have entered the realm of discrimination.

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[7] 476 U.S. 610 (1986).

[8] *See, e.g.*, Destro & Moeller, *Necessary Care for the Retarded Child: The Case of Phillip Becker*, 4 Human Life Rev. 81 (1980) *quoting* Transcript of Record, *In re* Phillip B., A Minor, No. 66103 (Super. Ct., Santa Clara County, Cal. Apr. 27, 1978), *aff'd*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 749 (1980).

[9] Though Chairman Allen's statement recounts that he voted against the adoption of this report, the record clearly shows that he abstained, thus acquiescing in the will of the majority. United States Commission on Civil Rights, Transcript of Meeting of Jan. 9, 1989 at 50 (remarks of Chairman Allen noting that he would probably abstain); *id.* at 58 ("That makes 7 votes aye, no votes against, and 1 abstention.") (quoting Chairman Allen's count of the Commissioners' votes). That Chairman Allen's approach to the issue of medical care discrimination is contrary to that of the Commission is clear from his written statement: he rejects the Commission's conclusions and minimizes its factual findings. Why he simply did not vote "no" remains a mystery.

[10] See comments of H. Tristram Engelhardt, Jr., Ph.D., M.D., appended to the statement of Chairman Allen. See also, *Hearing Before the United States Commission on Civil Rights: Protection of Handicapped Newborns* 79–112, 164–95 (1985) (vol. I).

And that, of course, is the crux of this debate. Were a physician, judge or ethicist to so much as suggest, orally or in print, that race or sex-based denial of medically indicated treatment might be justifiable for any reason, the public outcry for Federal, State, local (and, in some quarters, Divine) oversight, investigation and intervention would be heard round the world.

Yet there is a difference when the object of discrimination has a physical or mental disability. Noted physicians and medical centers have advertised their discriminatory attitudes and practices, and civil libertarians who should know better rush to defend the ability (some would say "the right") to engage in such discrimination. There is something seriously wrong—morally and legally—when physicians and ethicists concoct "quality of life" formulas so that they might confer a scientific patina on what is essentially medical discrimination (or worse). How many bodies does one need to count as "proof" when those involved admit to discrimination based on non-medical factors? This is the greater context in which this report should be read. The United States is at an ethical crossroads. A recent survey of 2,218 Colorado physicians concluded that 60 percent of all doctors have attended patients for whom they believe active euthanasia to be justifiable if it were legal, and 58.9 percent of these physicians "indicated that they would have personally been willing to administer a lethal drug if such measures were allowed by law."[11] California voters were asked, and refused by a wide margin, to approve a ballot initiative which would legalize "death assistance" (including lethal injections under certain circumstances),[12] and similar initiatives are planned for Florida, California, Oregon, and Washington in 1990.[13] To assume that the first candidates for such "assistance" are not going to be the disabled, the incompetent, and the elderly is naive.[14]

Other countries have already made their choice. It has been reported that some doctors in the Netherlands perform between 5,000 and 10,000 cases of direct euthanasia per year,[15] protected by court decrees which allow it when a patient makes an informed request.[16] The March 30, 1989, issue of the *New England Journal of Medicine* contains a both plea for the "wide and open discussion" of physician-assisted suicide, and a sympathetic, yet cautious, treatment of "the role that euthanasia may have in the treatment of the terminally or hopelessly ill patient."[17]

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[11] Center for Health Ethics and Policy, Graduate School of Public Affairs, University of Colorado at Denver, Withholding and Withdrawing Life-Sustaining Treatment: A Survey of Opinions and Experiences of Colorado Physicians (May 1988) at 16 [hereafter Colorado Survey]. The center recommended that the Governor should appoint a commission to evaluate, among other things, whether the substantial number of physicians holding these views represent "changing community mores" and urged reevaluation of present Colorado law forbidding active euthanasia to determine whether it is consistent with "the perceptions of right and wrong" of the people of the State. *Id.* at 21.

[12] "Euthanasia Law Fails to Qualify for Ballot," NEXIS PR Newswire, May 10, 1988 (Hemlock Society news release).

[13] U.P.I., "Right-to-Die Group Targets Florida in Ballot Drive," NEXIS, Aug. 1, 1988 (noting Hemlock Society plans to seek assisted suicide initiative in Florida, California, Oregon, and Washington).

[14] In Gilbert v. State, 487 So.2d 1185, 1190–91 (Fla. App., 4th Dist., 1986), a Florida court was recently asked (but refused) to rule that intent to commit euthanasia was a defense to a charge of premeditated murder. The offense: the convicted murderer had fired two bullets into the brain of his wife, who had the misfortune of being afflicted with osteoporosis and Alzhiemer's disease. Roswell Gilbert's case was recently the subject of a made-for-TV movie.

[15] G.T. van der Werf, *Huisarts en euthanasie*, 43 Medisch Contact 1389 (1986) and personal communication of P. Admiraal, cited in S. Wanzer, D. Federman, S.J. Adelstein, C. Cassel, E. Cassem, R. Cranford, E. Hook, B. Lo, C. Moertel, P. Safar, A. Stone, & J. van Eys, *The Physician's Responsibility Toward Hopelessly Ill Patients*, 320 New England J. Med., 844, 848 & n.28. (hereafter, S. Wanzer et al.).

[16] G.E. Pence, Ph.D, *Do Not Go Slowly into that Dark Night: Mercy Killing in Holland*, 84 Am. J. Med. 139 (1988) (estimating that, as of late 1987, between 5,000 and 8,000 patients have been killed by physicians in the Netherlands). A summary of the situation in the Netherlands, France, Denmark, the Federal Republic of Germany, and Sweden is contained in British Medical Association, Euthanasia: Report of the Working Party to Review the British Medical Association's Guidance on Euthanasia, at 49-52. With respect to the Dutch, paragraph 210 of the report concludes that "[i]t therefore seems that, although certain members of Dutch society are against active termination of life for cogent reasons, there is a widespread use of active termination of life, which is motivated by the highest humanitarian ideals but not all of which is reported." The BMA's position on the topic of euthanasia was unequivocal: "The active intervention by anybody to terminate another person's lie should remain illegal. Neither doctors nor any other occupational group should be placed in a category which lessens their responsibility for their actions." *Id.*, Conclusion 4, at 67.

[17] S. Wanzer et al., *The Physician's Responsibility Toward Hopelessly Ill Patients*, 320 New Eng. J. Med., 844, 848–49 (noting the moral objections of two of the authors J.v.E. and E.H.C.).

Those who need evidence of the growing attitude that death itself is a "treatment" for those whose lives are not of sufficient "quality" need only look to the record of the Commission's hearing, the medical literature, and the cases to see that what the Chairman of this Commission decries as unsubstantiated is freely admitted by those involved. There would be no point in arguing for a "wide and open" discussion of the topic were it not assumed from the outset that the acceptance of euthanasia is good public policy.

Justice James A. Andersen of the Supreme Court of Washington has written:

> As recently as five years ago, or perhaps three, the idea that fluids and nutriment might be withdrawn, with moral and perhaps legal impunity, from dying patients, was a notion that would have been repudiated, if not condemned, by most health professionals. They would have regarded such an idea as morally and psychologically objectionable, legally problematic, and medically wrong. The notion would have gone "against the stream" of medical standards of care. [However,]. . .this practice is receiving increased support from both physicians and bioethicists. This new stream of emerging opinion is typically couched in the language of caution and compassion. But the underlying analysis, once laid bare, suggests what is truly at stake: That for an increasing number of patients, the benefits of continued life are perceived as insufficient to justify the burden and cost of care; that death is the desired outcome, and critically—that the role of the physician is to participate in bringing this about.[18]

Justice Edward D. Robertson, Jr. of the Missouri Supreme Court has made the same point.[19]

Though the Washington State and Missouri cases deal with disabled adults, the basic issues are similar (though not identical) to those involving disabled infants like Baby Doe and Baby Jane Doe. The individual has a medical need which will respond to treatment, but is disabled and the prognosis for rehabilitation or cure is at best uncertain and usually bad. The treatments proposed are not medically contraindicated. The affected individuals are not dead or dying. The argument is over whether or not they might not be "better off" dead.

Recognizing the Obvious: The Abortion "Connection"

At the outset of both hearings, and in many of the debates, both internal and external to the Commission, the so-called "Baby Doe" issue has been linked to that of abortion. That it should not have been is an entirely different matter, but it is unsurprising that it was. Whenever the politics and law of civil rights, personal autonomy and bioethics confront one another in a field fraught with emotion, human suffering, and deeply-held and divergent moral views, connections will inevitably be made by those termed "liberals" as well as by those who style themselves as "conservatives" or "libertarians." That is what happened here.

And therein lies the most interesting, and personally frustrating, political aspect of this report. The witness list of the June 1985 hearing, assembled by Commission staff, cast the issues as matters of bioethics, medicine, and personal privacy. Discrimination was not the subject of the inquiry. When queried, the medical and ethical experts called to testify quite predictably denied that discrimination has anything to do with denial of treatment. The issue of discrimination was addressed directly by only one panel in the first hearing.[20] The focus on medicine and ethics and the relegation of disability or rehabilitation issues to the sidelines spoke volumes. The issue had been "medicalized" and "privatized."

It was not until the June 1986 hearing that disability and rehabilitation issues were highlighted. Testimony of parents and medical experts was included as well in an attempt to "balance" the record of both hearings. But then the libertarians on the Commission's staff took over. Firm believers in deregulation, they sat on the transcript of the 1986 hearing, refusing to release it even to this Commissioner, for nearly a full year. Considerable political capital was expended in an attempt to kill the report as late as August 1987. In short, the internal opposition of key staff members to the publication of this report largely accounts for its late release. For some, personal liberty was the motivating reason for their opposition; for others, it was the "abortion connection" which complicated an objective review of the record. Sadly, neither group ever stopped to consider whether there might really be discrimination going on.

Commissioner Mary Frances Berry captured the nature of the dilemma best shortly before she cast her (much appreciated) vote for this report and its recommendations.

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[18] *In re* Guardianship of Grant, 109 Wash.2d 545, 747 P.2d 445, 459 (1987) (Andersen, J., concurring in part and dissenting in part).

[19] Cruzan v. Harmon, 760 S.W.2d 408 (Mo., 1988).

[20] *Hearing Before the United States Commission on Civil Rights: Protection of Handicapped Newborns* 113–38 (1985) (vol. I) (disability perspective).

> I don't know if my colleague, Mr. Destro, has read [the Chairman's written comments on the report[21]], but if he has he will note that while he may think this issue has nothing to do with abortion, the Chairman seems to think it does and there are other people who I also think will think that it does, however you characterize it,. . . .[22]

She was (and is) correct. There is a connection. But it is not the political linkage one about which she and others have been so concerned. The nexus is philosophical and moral.

There will always be profound moral, philosophical, ethical and legal dilemmas involved in medical decisionmaking. Each of these dilemmas, in its own way, detracts from the personal choice and autonomy of those involved, but there is no escaping them.

It is also true that the law cannot prevent child abuse or any other anti-social behavior, such as discrimination, which has its roots in human ignorance, intolerance or weakness. The role of law is state a norm of acceptable behavior. Those who make and enforce the law can affect attitudes only as "teachers" whose pronouncements and behavior set the social norm. Thus, when the time comes for action, as it did for the Commission when it voted on this report, our duty to advise Congress and the President on policy required us to draw lines in as clear a fashion as our limited capacity for human understanding would permit.

This report rejects discrimination against the persons with disabilities in the context of medical care decision-making. To have ignored the problem, treated it as a matter of medical or parental autonomy, or minimized the seriousness of the attitudes which brought these practices about would have been to take the risk that the public might believe "that [this Commission thinks] it is alright to kill kids—[because] that is one way one could interpret [it]."[23]

Arlington, Virginia
May 1989

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[21] United States Commission on Civil Rights, Transcript of Meeting of Jan. 9, 1989 at 16.

[22] *Id. at* 19 (comments of Commissioner Berry).

[23] *Id. at* 20–21 (comments of Commissioner Berry).

Appendix A

Incidence of Congenital Anomalies

Table 1

Incidence of Selected
Congenital Anomalies Among Live Births in 1983 1/

	Total		White		Other	
Congenital Anomaly	Rate/ 10,000	Number	Rate/ 10,000	Number	Rate/ 10,000	Number
Central Nervous System						
Anencephalus	1.9	691	2.0	581	1.8	132
Spina Bifida w/out Anencephalus	4.8	1747	5.1	1481	3.9	287
Hydrocephalus w/out Spina Bifida	5.8	2111	5.5	1597	6.7	492
Encephalocele	1.1	400	1.1	319	1.1	81
Microcephalus	2.5	910	2.2	639	3.8	279
Cardiovascular						
Common Truncus	0.3	109	0.3	87	0.2	15
Transposition of Great Atresia	1.1	400	1.2	349	0.9	66
Tetralogy of Fallot	1.1	400	1.2	349	1.0	73
Ventricular Septal Defect	17.1	6223	17.5	5083	15.4	1131
Atresia Septal Defect	2.1	764	2.1	610	2.0	147
Endocardial Cushion Defect	0.8	291	0.7	203	0.8	59
Pulmonary Valve Stenosis & Atresia	1.9	691	1.5	436	3.4	250
Tricuspid Valve Stenosis & Atresia	0.3	109	0.3	87	0.3	22
Aortic Valve Stenosis & Atresia	0.6	218	0.6	174	0.5	37
Hypoplastic Left Heart Syndrome	0.8	291	0.8	232	1.0	73
Patent Ductus Ateriosus	29.6	10772	26.9	7813	39.6	2910
Corctation of Aorta	0.7	255	0.8	232	0.5	37
Pulmonary Artery Anomaly	2.0	728	1.4	407	3.9	287
Lung Agenesis & Hypoplasia	3.2	1165	3.2	929	3.0	220

Table 1 (Cont'd)

Incidence of Selected Congenital Anomalies among Live Births in 1983

	Total		White		Other	
	Rate/ 10,000	Number	Rate/ 10,000	Number	Rate/ 10,000	Number
Congenital Anomaly						
Gastrointestinal						
Tracheo-esophageal Anomalies	2.1	764	2.3	668	1.4	103
Rectal & Intestinal Atresia	3.5	1274	3.6	1046	3.1	228
Renal Agenesis	1.8	655	1.9	552	1.3	96
Bladder Exstrophy	0.3	109	0.3	87	0.2	15
Musculoskeletal						
Clubfoot w/out CNS Defects	26.1	9498	27.4	7958	21.1	1550
Reduction Deformity Upper Limbs	1.6	582	1.7	494	1.3	96
Reduction Deformity Lower Limbs	0.9	328	0.9	261	0.8	59
Congenital Arthrogryposis	2.2	801	2.4	697	1.5	110
Chromosomal						
Down Syndrome	8.5	3093	8.7	2527	8.0	588
Trisomy 13	0.8	291	0.8	232	0.6	44
Trisomy 18	1.0	364	1.0	290	1.1	81

Source: Centers for Disease Control: Congenital Malformation Surveillance Report, January 1982 - December 1985

Notes:

1/ Incidence rates are averages for the period 1982-85 as reported in Table 2 of the above mentioned source. These rates are based on live and still births and, therefore, overstate the rates for live births alone. Only in the case of anencephalus is the difference significant: in this case the live born rate reported in Table 5 was recorded for "total" births and rates for "whites" and "others" were calculated to reflect the comparative rates for anencephalus in Table 2.

The number of cases of each anomaly is a population estimate derived by multiplying the rate by total births in 1983.

Table 2

Deaths Caused by Congenital Anomalies in 1983 1/

	Number of Deaths for which Anomaly is the Underlying Cause				Underlying and Contributing Cause Total
	Age				
Congenital Anomaly	Under 1 Year [1]	1–4 Years [2]	Total [3]	[1]/[3] X 100 [4]	[5]
Central Nervous System	**1368**	**173**	**1892**	**72%**	**n/a**
Anencephalus	693	7	702	99	729
Spina Bifida	122	25	197	62	339
Hydrocephalus	227	61	382	59	564
Encephalocele	70	4	81	86	124
Microcephalus	50	33	138	36	282
Cardiovascular	**4400**	**535**	**7111**	**62%**	**n/a**
Common Truncus	112	7	136	82	167
Transposition of Great Arteries	157	39	253	62	326
Tetralogy of Fallot	98	65	253	39	317
Ventricular Septal Defect	194	56	502	39	962
Atrial Septal Defect	53	13	256	21	508
Endocardial Cushion Defect	114	71	223	51	326
Pulmonary Value Atresia & Stenosis	19	2	31	61	63
Tricuspid Atresia & Stenosis	27	14	71	38	97
Aortic Valve Insufficiency or Stenosis	54	4	176	31	258
Hypoplastic Left Heart	574	6	583	98	642
Patent Ductus Arteriosis	108	0	149	72	478
Coarctation of Aorta	152	4	187	81	292
Pulmonary Artery Anomaly	99	14	148	67	292
Agenesis of Lung	773	2	782	99	1516
Cleft Palate & Cleft Lip	**15**	**0**	**15**	**100%**	**n/a**
Cleft Palate	7	0	7	100	56
Cleft Lip (Total)	8	0	8	100	65

Table 2 (Cont'd.)

Deaths Caused by Congenital Anomalies in 1983 1/

	Number of Deaths for which Anomaly is the Underlying Cause				Underlying and Contributing Cause Total
	Age				
Congenital Anomaly	Under 1 Year [1]	1–4 Years [2]	Total [3]	[1]/[3] X 100 [4]	[5]
Gastrointestinal	**148**	**47**	**315**	**47%**	**n/a**
Tracheo-esophageal Fistula	20	2	29	69	106
Rectal, Large Intestine Atresia or Stenosis	5	0	5	100	71
Genitourinary	**498**	**4**	**890**	**56%**	**n/a**
Renal Agenesis	401	0	423	95	617
Bladder Exstrophy	1	0	1	100	12
Musculoskeletal	**738**	**20**	**845**	**87%**	**n/a**
Clubfoot*	0	0	0	–	30
Reduction Deformities of Upper Limbs	1	0	1	100	9
Reduction Deformities of Lower Limbs					
Chromosomal	**727**	**56**	**952**	**76%**	**n/a**
Down Syndrome	84	31	272	31	942
Trisomy 13	198	6	204	97	244
Trisomy 18	328	12	343	96	415
All Congenital Anomalies	**8732**	913	13173	**66%**	**n/a**

Source: Unpublished tabulations provided by the National Center for Health Statistics.

Notes:

1/ n/a-not available

Column 1 – Number of children under 1 year whose underlying cause of death was the indicated congenital anomaly.
Column 2 – Same as Column 1 for children 1–4 years.
Column 3 – Same as Column 1 for all ages.
Column 4 – Column 1 as a percentage of Column 3.
Column 5 – Total number of deaths for which indicated congenital anomaly was either the underlying or a contributing cause.

Underlying cause of death is defined as: "(a) the disease or injury which initiated the train of events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury." Article 23 of the Constitution of the World Health Organization.

Table 3

Infant Deaths in 1983 Caused by Congenital Anomalies Adjusted for Racial Differences in Births and Occurrence Rates 1/

	Infant Deaths		Nonwhite Infant Deaths Adjusted for Racial Differences in:	
Underlying Cause of Death	White [1]	Other [2]	Births [3]	Births plus Anomaly Occurrence Rates [4]
Central Nervous System	**1144**	**224**	**885**	**n/a**
Anencephalus	602	91	359	398
Spina Bifida	81	14	55	72
Hydrocephalus	172	55	217	178
Encephalocele	55	15	59	59
Microcephalus	44	6	24	14
Cardiovascular	**3453**	**947**	**3741**	**n/a**
Common Truncus	89	23	91	137
Transposition of Great Arteries	136	21	83	110
Tetralogy of Fallot	79	19	75	83
Ventricular Septal Defect	145	49	193	220
Atrial Septal Defect	42	11	43	45
Endocardial Cushion Defect	98	16	63	55
Pulmonary Value Atresia & Stenosis	14	5	20	9
Tricuspid Atresia & Stenosis	21	6	24	24
Aortic Valve Insufficiency or Stenosis	47	7	28	34
Hypoplastic Left Heart	457	117	462	370
Patent Ductus Arteriosis	79	29	115	78
Coarctation of Aorta	127	25	99	158
Pulmonary Arteries Stenosis	82	17	67	24
Agenesis of Lung	625	148	585	626

Table 3 (Cont'd.)

Infant Deaths Caused by Congenital Anomalies in 1983
Adjusted for Racial Differences in Birth and Occurrence Rates 1/

	Infant Deaths		Nonwhite Infant Deaths Adjusted for Racial Differences in:	
Underlying Cause of Death	White [1]	Other [2]	Births [3]	Births plus Anomaly Occurrence Rates [4]
Gastrointestinal	110	38	150	n/a
Tracheo-esophageal Fistula	16	4	16	26
Genitourinary	430	68	269	n/a
Renal Agenesis	353	48	190	277
Musculoskeletal	631	107	423	n/a
Anomalies of Diaphram	429	60	237	n/a
Chromosomal	589	138	545	n/a
Down Syndrome	64	20	79	86
Trisomy 13	165	33	130	173
Trisomy 18	267	61	241	219

Source: Unpublished tabulations provided by the National Center for Health Statistics. Centers for Disease Control: Congenital Malformations. Surveillance Report, January 1982 - December 1985.

1/ Infant refers to a child under 1 year of age.

Column [3] = Column [2] X 3.95, where 3.95 = white births/nonwhite births.

Column [4] = Column [3] X R where R, is the occurrence rate of a specific congenital anomaly among white children divided by the occurrence rate among children of all other races (Source: Table 1).

Appendix B

Statement of H. Rutherford Turnbull III* on Incidence of Discriminatory Denial of Medical Treatment

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My purpose today is to bring to the attention of the Commission evidence of a contemporary attitude in the medical profession that supports discrimination in medical care against children, particularly newborns with moderate to severe/profound disabilities. This predisposition toward discrimination, if carried out, will result in unwarranted deaths and indeed has been linked to unwarranted deaths. Such an attitude and behavior is sufficient to justify federal action to *prevent* discrimination from being carried out.

In addition, there is a very real need, as I will indicate, for the federal government to monitor hospital Human Rights Committees and Infant Care Review Committees to determine precisely what role they play, if any, in combatting or authorizing nontreatment that constitutes abuse under the Child Abuse Act Amendments of 1984, under state statutes or other state law, under equal protection doctrines, and under Section 504 to the extent that it now still applies to children and medical decisions. Given the physician attitudes and incidence data to which I will refer below, there is reason to believe, as Dybwad points out (Dybwad, *Ethical and Legal Problems in Rehabilitation and Medicine,* in Warms, D. (ed.) (1986), The Changing Rehabilitation World: Into the 21st Century. New York: United Cerebral Palsy of New York City, Inc.), that such committees "may serve well in institutions with good practices, but will serve poorly where they are most needed." And, further, there is *no* reason to believe that such committees will be independent of the physicians and hospitals whom they purport to review. Until such time as data are available and persuasive that the HRCs and ICRCs in fact play a salutary role in preventing discrimination, they may not be assumed to do so.

Finally, there also is a very real need—both human and legal—for the federal government to expand its support of adoption, foster-care placement, and even interim institutionalization for newborns or others whose biological parents refuse to allow them to be treated. While the prospect of legitimizing such institutionalization is thoroughly distasteful, it is less noxious than tolerance of nontreatment of treatable children, namely, those identified by the Child Abuse Act Amendments of 1984 and by the widely adopted Principles of Treatment of Disabled Infants, which I helped draft. Naturally, a far more desirable federal role is helping states to expand the adoption and foster-care placements of such children. Any of these alternatives—and all of them in the aggregate—make it possible for treatable children to be treated and for unjustifiable and prejudicial parental and physician objections to be functionally voided.

A 1975 survey of representative pediatric surgeons and pediatricians conducted by the Surgical Section of the American Academy of Pediatrics disclosed that 76.8 percent of the surgeons and 49.5 percent of the pediatricians would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia if the infant also had Down's syndrome." Shaw, Randolph and Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatrician and Pediatric Surgeons,* 60 Pediatrics 588, 590 (1977). And 63.3 percent of the surgeons and 42.6 percent of the pediatricians said that in such cases where they "accept parental withholding of lifesaving surgery" they would also "stop all supportive treatment including intravenous fluids and nasal gastric suction." *Id.* at 592–93. Another 1975 survey, this one of California pediatricians, showed that 61 percent would not object to a parental decision not to correct a life-threatening intestinal obstruction of an infant with Down's syndrome. *Treating the Defective Newborn: A Survey of Pediatricians Attitudes,* Hastings Ctr. Report, April 1976, at 2. A 1977 survey of Massachusetts pediatricians disclosed that 51 percent believed that such a child should not receive surgery. Todres, Krans, Howell and Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns,* 60 Pediatrics 197, 198 (1977). Even among the 46 percent who would advocate surgery, only 40.2 percent (18.3 percent of the full group of pediatricians) would pursue a court order to secure treatment. Sixty-seven percent (67 percent) of the pediatricians would recommend no surgery for a child with severe myelomeningocele (spina bifida). Of those who advocate surgery, 60 percent said they would allow the parents to withhold surgery. *Id.* at 198–99.

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* **Professor of Special Education and Law, University of Kansas, Lawrence, Kansas, statement made to the U.S. Civil Rights** Commission, June 26, 1986.

A study covering the period from 1977 to 1982 and a more recent survey reinforce this data. CAVC (complete atrioventricular canal defect) is a heart malformation which usually leads to pulmonary vascular disease and premature death. Open heart surgery can correct the malformation and avert the death, and a technique known as pulmonary artery banding can delay the need for this surgery until a child is mature enough to tolerate it. Prompt referral of infants with CAVC to cardiac care facilities for this treatment is vital, since delay can result in the development of irreversible pulmonary vascular disease, when lifesaving surgery is impossible. During the years 1977 through 1982, pediatric cardiologists at the State University of New York-Upstate Medical Center in Syracuse were referred 8 children with CAVC but without Down's syndrome and CAVC at an appropriately early age. However, 10 children with CAVC and Down's syndrome were not referred until between 19 months to 15 years of age. By the time they were referred, 5 of these 10 children with Down's syndrome had deteriorated to a point at which surgery could not be performed. The physicians who reported the study wrote, "Some of our patients with late referral were initially evaluated elsewhere, and informed that surgical procedure was not recommended or not available (by parental report). We question if the parents of these children were being allowed the opportunity to make an appropriate decision." Sondheimer, Byrum and Blackman, *Unequal Cardiac Care for Children with Down's Syndrome,* 139 Am. J. Dis. Child. 68, 70 (1985). They concluded, "Children with treatable medical conditions should not be denied routine care because of other handicapping conditions. . .our review of CAVC in children with and without Down's Syndrome suggests that just such a denial of care may have occurred in some instances between 1977 and 1982." *Id.* at 70.

Still more recently, a 1984 survey of nurses at two hospitals in Houston indicates that denial of treatment to children with disabilities remains an accepted practice. Berseth, Kenny and Durand, *Newborn ethical dilemmas: Intensive care and intermediate care: Nursing attitudes,* 12 Crit. Care 508 (1984). The nurses surveyed either worked in neonatal intensive care units (ICUs) or in intermediate care nurseries (INTs). Of those surveyed (75 respondents, 39 from ICUs and 36 from INTs), 70.6 percent (53, 32/21) said they felt an infant with severe mental defects should never be resuscitated. (Examples of severe mental defects were given as anencephaly or severe brain damage.) Forty-eight percent (36, 21/15) would only occasionally resuscitate an infant with a severe defect (examples were congenital hydrocephalus and myelomeningocele, popularly known as spina bifida). The percentage of those responding that infants with severe defects should never be resuscitated was 13.3 percent (10, 3/7). An interesting side note is that one respondent from an intermediate care nursery felt that even infants with only minor birth defects (examples given were skin tags or extra digits) should never be resuscitated. *Id.* at 509. Also, 37 percent of the nurses felt that sometimes a doctor should act in such a way as to cause an infant's death. Thirty-one percent believed that the decision on whether to treat a sick newborn should be influenced by the presence of healthy children at home. *Id.* at 509.

I myself have recently completed a review of the literature concerning the incidence of infanticide in America and the public and professional attitudes toward the treatment/nontreatment of children born with birth defects. I wish to summarize what I found and reported (H. Turnbull, *Incidence of Infanticide in America: Public and Professional Issues,* 1 Issues in L. & Med. 363 (1986)).

1. Public attitudes toward persons with mental or physical disabilities are largely negative (p. 364).

2. Stigma and discrimination go hand in hand in contemporary America (p. 365).

. . . .

5. Professional attitudes concerning children with disabilities are variable. Some disability professional organizations (such as AAMD and TASH) have adopted resolutions objecting to the withholding of medical care and treatment on the sole basis of disability; others (AAMD, TASH, AAUAP) have advocated in the United States Supreme Court for the application of Sec. 504 to newborns; and some (AAMD, AAP) have signed the 1984 Principles of Treatment of Disabled Infants (p. 371). Most parent-advocacy organizations (ARC, TASH, NDSC) take similar positions (p. 371). Disability-related professional and parent-advocacy organizations were nearly unanimous in supporting a policy that would put a halt to nontreatment (p. 372).
6. Medical associations did not aggressively pursue a federal role (p. 372).
7. Reported attitudes of physicians are overwhelmingly negative concerning the mandate to treat treatable newborns (p. 374, esp. notes 69–72, 80–85, 87). I wrote, "Absent more comprehensive research about physician attitudes, it is difficult to make a broad generalization about current physician attitudes and their relationship to nontreatment. The history of reported attitudes, however, is negative. They reflect unjustified pessimism about the quality of life of the child and family and advocate criteria for nontreatment that are more pessimissive than those of the 'Principles of Treatment' (p. 379)."

My basis for that conclusion was not merely the research that I have just cited. It also included Adams' 1982 report that physicians' advice concerning services is influenced by parents' socioeconomic status, the physicians' years in practice, the population of the town where the physicians practice, and the physicians' participation in training in mental retardation (Adams, *Referral Advice Given by Physicians*, 20 Mental Retardation 16 (1982)). Further, it included Wolraich and Sipperstein's 1983 conclusion, based on inquiries of physicians, that physicians are significantly more pessimistic than psychologists, educators, allied health professionals, and social workers toward the prognosis for individuals with mental retardation (Wolraich and Sipperstein, *Assessing Professionals' Prognostic Impressions of Mental Retardation*, 21 Mental Retardation 8 (1983)).

Voices have been heard to claim that the data I have just reviewed are outdated and no longer relevant. The former President of the American Academy of Pediatrics, Dr. James Strain, has objected that his organization's 1975 survey is no longer relevant. "Since then," he has written, "I believe there has been a major shift in the attitude of the medical profession and of society as a whole concerning the care of mentally retarded infants in the nursery and in later life." Deinstitutionalization, the passage of the Education for All Handicapped Children Act, and the "change" in "society's concern for the care of children" which has led to a recognition that children sometimes must be protected from abusing parents have resulted in a consensus that "in cases in in which well-established surgical techniques have proven successful in correcting the defect, retardation, or other handicapping condition should not preclude treatment." Strain, *The Decision to Forego Life-Sustaining Treatment for Seriously Ill Newborns*, 72 Pediatrics 572 (1983). This change in societal attitudes, according to Strain, has had an effect on pediatricians' attitudes "in making decisions to recommend surgical correction of associated defects and to continue life support treatment in handicapped infants." *Id.* at 572.

In his testimony before this Commission on June 12, 1985, Dr. Strain stated he felt infants with Down's syndrome and spina bifida were now almost universally accorded treatment by the medical profession. He specifically stated that "all of the pediatric literature favors supporting corrective surgery for [infants with] Down's syndrome" and "most babies with spina bifida are treated" with surgery. *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* (June 12–14, 1985) (Statement of James Strain, M.D., past president, American Academy of Pediatrics) at 47.

Were Dr. Strain's view correct, one would expect to see it substantiated in the recent medical literature. On the contrary, however, the recent commentary on the issue is overwhelmingly in favor of denying treatment to those deemed to lack a sufficient "quality of life." Beyond the evidence of the quite recent 1984 survey I have described, books and articles authored or coauthored by physicians that insist quality of life must be taken into account in treatment decisions and that argue a low quality of life ethically justifies or even mandates letting some children with disabilities die are legion.

Dr. Robert M. Blizzard, chairman of the Department of Pediatrics at the University of Virginia School of Medicine, has written, "The ethic of many [pediatricians] is (and we believe it justified) that the quality of life in some instances should take precedence over the equality of life." Blizzard, *The Pediatrician: Advocate or Enemy of the Child,* HELIX Autumn 1984, *quoted in* Cooper, *The Pediatrician Is the Child's Advocate,* 60 J. Med. Educ. 496, 497 (1985). According to a 1983 piece by Marcia Angell, M.D., Deputy Editor of the New England Journal of Medicine, "[t]he premise that the quality of life has no bearing on medical decisions. . .is a dubious premise. It is in direct conflict with most current thinking about medical ethics." Angell, *Handicapped Children: Baby Doe and Uncle Sam,* 309 N. Eng. J. Med. 659 (1983). It is the current and official position of the Judicial Council of the American Medical Association that, "In the making of decisions for the treatment of seriously deformed newborns. . .[q]uality of life is a factor to be considered. . . ." *Current Opinions of the Judicial Council of the American Medical Association* 2.14, at 10 (1984). This opinion was also contained in the AMA's statement to the House Select Education Committee, opposing a bill that in modified form would become the Child Abuse Amendments of 1984. *Statement of the American Medical Association to the Select Education Sub-Committee, Committee on Education and Labor, House of Representatives,* 47 Conn. Med. 29, 29 (1983).

A piece by Dr. George Crile, former head of the Department of General Surgery of the Cleveland Clinic, was widely reprinted in December of 1984 in a number of medical newspapers and then in *USA Today.* Dr. Crile wrote:

> The law now states that in obstetrical units, babies must be fed and given full support regardless of how extensive and hopeless their congenital malformations. Despite the law, the debate. . .continues. . . .[The question] must be viewed not only in the light of the individual's right to life, but in that of society's right for its members to have pleasant and productive lives, not to be lived mainly to support the growing numbers of hopelessly disabled, often unconscious people whose costly existence is consuming so much of the gross national product. . . .
>
> No child with Down's syndrome ever grew up to be self-sustaining. . . .If the parents still want to rear their child, that should be their decision, but there should be no support from the community or the state.

Crile, *The Right to Life,* Medical Tribune, Dec. 19, 1984, at 27.

In a March 6, 1986, editorial in the New England Journal of Medicine, Angell stated, "Quality of life is an important consideration as the weight of our ethical, medical and legal traditions suggests." Angell, *The Baby Doe Rules,* 314 N. Eng. J. Med. 642 (1986).

A 1983 editorial in *Surgical Rounds* stated:

> Take the simplest case of the Down's Syndrome child with esophogeal or duodenal atresia (like Bloomington's Infant Doe). With luck his life can be saved, and he can be trained to the point of being a happy family pet. But the break-up rate in families whenever a grossly abnormal child is brought home is very high.

Ravitch, *Big Brother Comes to the Nursery,* 6 Surgical Rounds 10, 10 (1983).

Dr. Steven Ragatz and Dr. Patricia Ellison, from the Departments of Pediatrics and Neurology at the Medical College of Wisconsin, stated their position that "consideration should be given to withdrawal of support from infants who are. . .likely to be severely retarded and dependent later in their lives." Ragatz and Ellison, *Decisions to Withdraw Life Support in the Neonatal Intensive Care Unit,* 22 Clinical Pediatrics 729, 729 (1983).

> If one thought that these children had a quality of life representing that which one treasures as a human, perhaps the care and frustration of the parents would be justified. However, these children have very limited capacities for human relationships and participation in human experiences, criteria that others have considered for withdrawal of support.

Id. at 729.

Dr. John Britton, from the Department of Pediatrics, Section of Perinatal and Nutrition Science, University of Arizona Health Services, has written that decisions regarding treatment of handicapped infants should be made on a case-by-case basis, not mandated by legislation. J.R. Britton, *'Baby Doe' Rulings—Review and Comment,* 140 West. J. Med. 303 (1984). Further, "Quality of life considerations, desires and concerns of the parents and economic implications for the family and society must be weighed in the decision-making process." *Id.* at 306.

Anthony Shaw, M.D., professor of surgery and pediatrics, University of Virginia School of Medicine, has defined quality of life as the product of an infant's natural endowment and the contributions made to the child by the home and family unit and by the society as a whole. Shaw, *Defining The Quality of Life,* 7 Hastings Ctr. Rep. 11, 11 (1977).

In his testimony before this Commission, Dr. Shaw tried to justify his formula by saying that his intention was to "maximize those factors that would improve quality of life." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* (June 12–14, 1985) (Statement of Dr. Anthony Shaw) at 82. He claims to have been particularly motivated by the fact that Down's syndrome children often were placed in institutions.

> Back in the seventies, particularly early seventies, late sixties, many of us were discomfitted by the idea that we as pediatric surgeons could operate on these babies and open up their intestinal tract so that they could eat, and the parents would then through their own decision or suggestion to them by family, friends, pediatricians or whatever, turn the baby over to an institution. And those of us who took the trouble to look at these institutions were by and large horrified at the conditions that existed and the way babies were subsequently managed. *Id.* at 89.

However, Shaw's writings in that time period show a different point of view. In a 1972 article published in the *New York Times Magazine,* Shaw wrote of having seen "families emotionally and financially drained by mongoloid children" and "marriages destroyed by the inability of the partner to deal with. . .a mongoloid child." A. Shaw, *Doctor, do we have a choice?* New York Times Magazine, Jan. 30, 1972, 44. Later in the same article, he wrote:

> [T]he emotional and financial resources of many families are poured out for helpless retardates while children with real potential are stunted in institutions or a series of foster homes.
>
> Parents of mongoloids have the legal (and, I believe, the moral) responsibility of determining if their child with a potentially deadly but surgically correctible defect should live or die.

Id. at 52–53.

Shaw now claims that the sole purpose of his formula was to keep alive those infants who might otherwise not receive treatment and would die. However, in his article defining his quality of life formula, Shaw pointed to "a child born normally formed but. . .in an urban ghetto to an unwed teenage drug addict." If society did not provide for such a child, even with a "respectable quantity" of natural endowments, the child's quality of life would be worthless because, according to Shaw, nothing would be provided by the home. Shaw, *Defining the Quality of Life, supra,* at 11.

Shaw's formula [QL = NE × (H + S)] was used as the basis for initial decisions not to treat 33 infants with spina bifida over a 5-year period at Oklahoma Children's Memorial Hospital. Gross, Cox, Tatyrek, Pollay, and Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele,* 72 Pediatrics 450 (1983).

Writing in support of such a definition of quality of life and against "the federal government'[s]" effort to "declare severe mental impairment irrelevant to medical decisions" in mandating nondiscriminatory treatment for children with disabilities, Dr. Joel Frader, a pediatrician at Pittsburgh Children's Hospital, expostulated, "Why shouldn't non-medical considerations, like family and community resources, a family's religious beliefs, or similar factors become important to the decisions? Good reasons for permitting death may exist." Frader, *Treating Baby Doe Con: The Benefits Must be Weighted,* Pittsburgh Press, May 18, 1984, at 83.

The attitude of the Bioethics Committee of the American Academy of Pediatrics is that while treatment should not be withheld if the sole reason for doing so is to benefit the psychological or social well-being of others, if the infant's life is deemed to be one that will be filled with suffering, familial concerns are also to be used in the treatment decision.

> While the needs and interests of parents, as well as of the larger society, are proper concerns of the pediatrician. . .[w]ithholding or withdrawing life-sustaining treatment is justified only if such a course serves the interests of the patient. When the infant's prospects are for a life dominated by suffering, the concerns of the family may play a larger role. Treatment should not be withheld for the primary purpose of improving the psychological or social well-being of others, no matter how poignant those needs may be.

American Academy of Pediatrics, Committee on Bioethics, *Treatment of Critically Ill Newborns,* 72 Pediatrics 565, 566 (1983).

Irwin Krasha, M.D., Department of Pediatrics Surgery and Pediatrics, Rutgers University, asks us to "[t]hink about the family's right to happiness without this tragic creature [the seriously ill newborn] ruining their lives." Krasha, *The Infant: Right to Privacy and Patient's Right to Know,* 51 Mt. Sinai J. Med. 25, 25 (1984).

Dr. Blizzard argues that "it is wrong to prolong the life of an infant. . .who will never think, walk, or talk, when the parents decide that they and the infant's siblings cannot cope with such prolongation, and that prolongation is to the detriment of the family stability." Blizzard, *The Pediatrician: Advocate or Enemy of the Child,* HELIX, Autumn 1984, *quoted in* Cooper, *supra,* at 497 (1985).

Physicians often claim that life with a severe enough disability is a life of suffering. "Where treatment has a high probability of causing significant pain and suffering and a low probability of preserving a life valuable to the patient should we not permit a decision to withhold it?" Moskop and Saldanna, *The Baby Doe Rule: Still a Threat,* 16 Hastings Ctr. Rep. 8, 9 (1986). Moskop, associate professor of medical humanities, and Dr. Saldanna, assistant professor of pediatrics/neonatology, East Carolina University School of Medicine, feel there is a threat of "unjustified prolongation of life" to some handicapped children. *Id.* at 9.

Carol Lynn Berseth, M.D., from the Pediatrics Department at the Mayo Clinic, has written, "To offer extraordinary support to these infants [with severe handicaps] is to prolong their suffering by traumatizing them further with invasive techniques." Berseth, *A Neonatologist Looks at the Baby Doe Rule: Ethical Decisions by Edict,* 72 Pediatrics 428, 429 (1983). Angell wrote that decisions regarding treatment for newborns "properly include considerations of future suffering." Angell, *The Baby Doe Rules, supra,* at 643.

In Angell's 1983 editorial, she stated the issue involved in treatment decisions was "one of future suffering. Do we have the right to inflict a life of suffering on a helpless newborn just because we have the technology to do so. . .?" Angell, *Handicapped Children: Baby Doe and Uncle Sam, supra,* at 660. Kathlyn E. McGoldrick, M.D., editor of the *Journal of the American Medical Women's Association,* has written that the view of most physicians is "that aggressive management, which only prolongs the pain and suffering of a hopelessly impaired infant, is neither humane nor rational." McGoldrick, *Baby Jane Doe: questions and quagmires,* 39 J. Am. Med. Wom. Assoc. 67, 67 (1984).

Another reason given for the denial of treatment to children with disabilities is based on limited financial resources. An anonymous neonatalogist, writing in a popular magazine, protested that the "mandatory treatment of all infants with serious defects would soon exhaust the capacity. . .of all [Neonatal Intensive Care Units] in the country." Dr. "N," *Should This Baby Be Kept Alive. . .Who Can Best Decide?* Woman's Day, Apr. 24, 1984 at 69. *See also* Moskop and Saldanha, *supra,* at 12.

Dr. Ravitch has written that "at some point along the line the mere dollar cost of these efforts [to treat seriously ill newborns] will be questioned." Ravitch, *supra,* at 12. Ragatz and Ellison also stated that financial considerations should play a part in the determination of what treatment should be given: "[T]hat factor [finances] must be included in the analysis, especially at a time when programs for the handicapped are losing funding, community support services are disappearing, maintenance funds and services for institutionalized children are decreasing, and funds for health care are limited." Ragatz and Ellison, *supra,* at 729.

Dr. Britton also spoke of the increasing financial burdens that are likely to result from federal regulations on treatment of handicapped newborns.

> If current rulings are upheld, the cost to society could be enormous. Although the potential economic impact of Baby Doe rulings has not been assessed, the personal financial burden to parents of long-term home care for chronic problems and frequent physician visits and hospital admissions for acute problems to which many such infants are prone may be great. . .because intensive care is required for many defective newborns, increasing the number of such infants will likely necessitate expansion of both physical facilities and nursing and physician staff in neonatal intensive care nurseries. Such expansion of health care supply to meet an increase in demand is likely to occur slowly, if at all, and in the interim other infants requiring intensive care may either be denied admission to an intensive care unit or receive compromised care by overextended staff. The institution of Baby Doe regulations could precipitate a health care shortage of crisis proportions, compromising both the quality and quantity of that care.

Britton, *supra,* at 306.

The realities of neonatal intensive care units also contradict any assertion of a change in attitudes in the medical profession. Norman Fost, M.D., Assistant Professor of Pediatrics at the University of Wisconsin School of Medicine, has written, "It is common in the United States to withhold routine surgery and medical care from infants with Down's Syndrome." Fost, *Passive Euthanasia of Patients with Down's Syndrome,* 142 Arch. Inten. Med. 2295 (1982). Dr. Walter Owens, the physician who first counselled nontreatment for "Baby Doe" in Bloomington, testified at an April 13, 1982, hearing before Judge John Baker, that even if life-saving treatment had been administered, the infant would not have possessed what he considered a "minimally acceptable quality of life." Further he stated:

> [T]his would still not be [a] normal child. . .Some of these [Down's Syndrome] children. . .are mere blobs. . .[M]ost of them eventually learn to walk and most eventually learn to talk. . . .[T]his talk consists of a single word or something of this sort at best. . . .These children are quite incapable of telling us what they feel and what they sense, and so on.

Petition for Certiorari at 8, Infant Doe v. Bloomington Hospital, filed Sept. 13, 1983, *cert. denied* 104 S.Ct. 394 (1983).

Likewise, Dr. John Pless, the Bloomington baby's physician, has written: "The potential for mental function and social integration of this child, as of all infants with Down's Syndrome, is unknown." (Pless, *The Story of Baby Doe,* 309 New Eng. J. Med. 664 (1983)).

Further, the experience of the 5-year study performed at Oklahoma Children's Memorial Hospital is a resounding indication that physicians still feel that there are certain infants who should not be treated.

Of 69 infants with myelomeningocele who were admitted to the hospital, 33 (48 percent) were recommended for nontreatment. Of these 33, 5 were treated at the request of the parents, two were later treated aggressively, 1 was treated by crisis management, and there was no followup on 1. The remaining 24 children who were recommended for nontreatment died within 189 days after birth. Factors used to determine which infants would be treated included, among others, the existence of other handicaps which would prevent self-care as an adult and the economic and intellectual resources of the family. Gross, Cox, Tatyrek, Pollay, and Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele,* 72 Pediatrics 450, 451 (1983). During the 18 months following the 5-year study reported by the Oklahoma team, an additional 15 children were sent to the same shelter where the original 24 had died. All but one of these infants died before the shelter was closed by state officials for various health and safety violations. C. Sherwood, *Oklahoma "charnel house" held 38 infants sent to die,* in Baby Doe: The Politics of Death 9 (1984).

With respect to the actual incidence of selective nontreatment, abuse, and neglect, I noted in my article (Turnbull, *Incidence of Infanticide in America: Public and Professional Attitudes,* 1 Issues in L. & Med. 363 (1986)) that the data are scarce. They nonetheless exist. Set out below are excerpts from my article.

> **Incidence of Selective Nontreatment, Abuse, and Neglect**
>
> Here, again, the data are scant. Duff and Campbell reported that of 299 consecutive deaths in a special-care nursery, 43 (14%) were related to the withholding of treatment.[1] Hardman[2] has noted that, if those data are extrapolated to a national figure multiplied by the number of newborn intensive care nurseries in existence in 1973, the result would be that "several thousand infants a year" would not be treated and would have died during that year.
>
> The John Hopkins Hospital case also was reported that year, and the report intimated that the death of that one child is replicated at the hospital and elsewhere.
>
> The 1975 survey of pediatricians and pediatric surgeons,[3] the 1976 survey of the San Francisco physicians,[4] and the 1977 survey of Massachusetts physicians [5] concerned the Senate Committee on Labor and Human Resources. The Committee noted that, if, since 1975, physicians have been acting on their convictions, federal policy on the civil rights of handicapped people is being contravened[6] and presumably some children were dying because of selective nontreatment. The Senate Committee noted, quite properly that "incidence of actual denial on the basis of disability is difficult to document."[7] But it also cited the testimony of Dr. David M. McClone, Chairman, Department of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, that in 1983, 10 of 200 children born with spina bifida referred to his hospital for treatment "had been denied prompt surgical therapy" before transfer. Dr. McClone concluded, if that sample is nationally representative, approximately 5% of newborns with spina bifida (400 infants) are subjected to some form of nontreatment annually.[8] The Committee also reported Dr. Koop's testimony that, "in recent months" he had received "over

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[1] Duff, *Human Ambiguity, supra* note 81. [Editor's note: Footnote text is reprinted as it appeared in the article; the note numbers have been changed.]

[2] Hardman, *The Role of Congress in Decisions Relating to the Withholding of Medical Treatment from Seriously Ill Newborns,* 9 J. Assoc. Persons Severe Handicaps 3–7 (Spring 1984).

[3] Shaw, *Ethical Issues, supra* note 71.

[4] *Treating the Defective Newborn, supra* note 73.

[5] Todres, *supra* note 72.

[6] Senate Comm. on Labor and Human Resources, Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1983, S. Rep. No. 246, 98th Cong., 1st Sess. 9 (1983).

[7] *Id.*

[8] *Id.*

20 contacts" from nurses who objected to carrying out physicians' orders to deny food to handicapped newborns.[9]

Shurtleff and his colleagues[10] recommended aggressive treatment for all spina bifida children (if good intellectual prognosis is present), regardless of the level of the spinal lesion. Of 88 patients treated with supportive care, only 52 were born before 1965 (the "early" group). In 1965, the physicians began an evaluative process of newborns. They selected 36 of the 88 (40.9%) for only supportive treatment after 1965 (the so-called "younger" group). Of the 36, there were 34 whose parents accepted the initial recommendation of nonintervention; the children were discharged to nursing homes. Of the early group, 30% survived to be at least twenty years old and 10% of the younger group survived to be at least two years old. In other words, some babies survived in spite of the pessimistic initial evaluation.

A study by Feetham and his colleagues[11] noted that 31 of 75 newborns (41.3%) with spina bifida initially were not treated, but 70% of them were still alive at the age of eighteen months.

Wolraich[12] reported an evaluation of 27 babies with spina bifida who were followed over a three year period. Among them, 12 met Lorber's criteria as not qualifying for aggressive treatment; nonetheless, four families opted for vigorous treatment, and two of the four babies died within seven months. With respect to the other 8 in that nontreatment cohort of 12, 3 (25%) were treated subsequently, 5 (41.6%) were not, and 5 died.

Gross and his colleagues[13] reported in 1983 that, during a five year period beginning in 1977, 33 babies out of 69 (47.8%) who had spina bifida were subject to decisions about nontreatment. Five were initially treated at the parents' request, two underwent delayed vigorous treatment, one was subsequently treated by crisis management, one moved and dropped out of the study, and 24 (34.7%) received only supportive care and died between 1 and 189 days of life (mean, 37 days).

Fost[14] reported that it is "common in the United States to withhold routine surgery and medical care from infants with Down syndrome for the explicit purpose of hastening death."

Ragatz and Ellison[15] reviewed twenty "cases" in a neonatal unit at a university hospital in which the decision to withdraw treatment was made; they noted that these twenty children represented 2.7% of all neonatal intensive care unit (NICU) admissions during the sixteen months of their review.

Of course, some very strong inferences can be made from the reports of nontreatment. Horan and Robertson[16] have concluded that the practice of selective nontreatment apparently is "common" and "may be gaining status as 'good medical practice'" in America. Indeed, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research has endorsed selective nontreatment and reported that it occurs, without being able to say how often.[17]

Finally, the Department of Health and Human Services has reported that it has not been able to reach any finding of discrimination after investigating forty-nine cases of alleged discriminatory withholding of medical care during the few months that it was enforcing the Baby Doe regulations under Section 504.[18]

Here, then, is the situation. Some physicians elect not to treat some children. Some parents agree not to have their children treated. Some nontreated children (the majority) die sooner or later (usually sooner) after the nontreatment decision is made. It is not known for certain how many physicians elect not to treat, how many parents agree to nontreatment, how many physicians chose to treat and how aggressively they treat, how many parents agree to treatment and to aggressive treatment, how many children who are treated nonaggressively or aggressively survive, how long they survive, how they live once they survive, and whether selective nontreatment ever will be accurately reported, since some of it may be done covertly or outside of those facilities.

Furthermore, it is increasingly unlikely that there will be reliable research data about the incidence and consequence of nontreatment. The climate about nontreatment has changed (selective nontreatment seems less defensible in these days of a disability rights ethos) and because the laws concerning nontreatment have either been changed (as in the case of the federal child abuse laws) or seem to be more likely to be applied.

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[9] *Id.*

[10] Shurtleff, Hayden, Lowser & Kronmal, *Myelodysplasia: Decision for Death or Disability,* 291 New Eng. J. Med. 1005 (1974).

[11] Feetham, Tweed & Perrin, *Practical Problem in Selection of Spina Bifida Infants for Treatment in the USA,* 28 Kinderchair 301 (1979).

[12] Wolraich, *Medical, Ethical and Legal Issues in Selective Use of Rehabilitative Care in the Management of Children with Spina Bifida.* 2 Spina Bifida Therapy 213 (1980).

[13] Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision-Making for the Treatment of Myelomeningocele,* 72 Pediatrics 450 (1983).

[14] Fost, *Passive Euthanasia of Patients With Down's Syndrome,* 142 Arch. Inter. Med. 2295 (1982).

[15] Ragatz & Ellison, *Decisions to Withdraw Life Support in the Neonatal Intensive Care Unit,* 22 Clin. Pediatrics 729 (1983).

[16] Horan & Robertson, *cited* in Ethical, Moral and Legal Considerations on the Practice of Withholding Medical Treatment from Infants with Congenital Defects (P. Guess, B. Dussault, F. Brown, M. Mulligan & F. Orelove eds. (1984)).

[17] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment 217–223 (1983).

[18] 49 Fed. Reg. 1646–1649 (1984).

> There most likely is—and probably always will be—the occurrence of nontreatment of infants who, under the President's Commission's guidelines, the "Principles of Treatment" and the federal and state child abuse laws, nonetheless should be treated. Parental and physician attitudes about some disabled newborns will encourage and tolerate some underground practices of nontreatment.
>
> There will always be difficult line-drawing problems. There may be reasoned differences among medical experts whether a particular child should have been treated as a medical matter, assuming the experts are in consensus about the meaning of the applicable law. There also may be reasoned differences about the meaning of the law, without regard to its application. The fact that there may always be indefensible cases of nontreatment does not mean, in any way, that those cases should be tolerated. It simply means that, whatever little we know for certain today about the incidence of nontreatment, we are likely to know nothing more, and perhaps even less, about it in the future.

Ironically, this survey of contemporary medical literature is reinforced by the testimony offered before this very Commission in June 1985. Numerous witnesses gave their feelings on how treatment decisions should be affected by quality of life considerations. Mildred Stahlman is head of the Division of Neonatology at Vanderbilt University School of Medicine. In her testimony before this Commission, Dr. Stahlman stated that "an easily remedial surgical condition ought to be performed *if* it offers a relatively pain-free existence beyond that." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* (June 12–14, 1985) (Statement of Mildred Stahlman, M.D.) at 16 (emphasis added). She later testified that in making a treatment decision, consideration should be given to "whether or not the individual. . .has any humanness in the quality of their life." *Id.* at 16. Joseph Boyle, president of the American Medical Association, told the Commission that federal intervention through section 504 of the 1973 Rehabilitation Act would "create a state in which an infant will be forced to live in pain, spasticity, under heavy sedation and narcotics." *Id.* (Statement of Joseph Boyle, M.D.) at 48. Dr. Siva Subramanian, director of the nursery at Georgetown University Medical Center, indicated that, when the assessment of the doctors was that the treatment would "bring more pain and suffering without any benefit for that patient," withdrawal of life support systems would be discussed with the parents. *Id.* (Statement of Siva Subramanian, M.D.) at 91. According to Mary Anne Warren of the Department of Philosophy, San Francisco State University, it is impossible to avoid quality of life considerations. To her, the relevant question is whether the child will ever "have a level of human experience. . .beyond the simple capacity to suffer." *Id.* (Statement of Mary Anne Warren, Ph.D) at 150. Jeffrey Ponerance, director of neonatology at Cedars-Sinai Medical Center in Los Angeles, continued the support for quality of life considerations. He labelled the DHHS regulations allowing for the withdrawal of care if such care were futile, but not the withdrawal of care if the infant were handicapped, as "inappropriate reasoning." *Id.* (Statement of Jeffrey Ponerance, M.D.) at 180.

Critical to the quality of life, in the opinion of many of the witnesses at the 1985 hearings, were the societal and familial interests involved. Dr. Cynthia Barrett, director of the Newborn Intensive Care Unit and head of neonatology at UCLA Medical Center, spoke directly to the costs to the family by saying, "[T]heir emotional costs [after the birth of a child with disabilities] are very high. They see a child over whom they have not control, whom they cannot carry, handle, nurture . . . .[F]urther, the financial costs are inordinate." *Id.* (Statement of Cynthia Barrett, M.D.) at 93. Dr. Subramanian testified that the question of treatment for infants was one of "familial autonomy in terms of the family as a unit, and the parents in the best interests of the patient will be able to express their opinion in terms of autonomy." *Id.* (Statement of Siva Subramanian, M.D.) at 90. Later during the hearings, Joy Penticuff, Associate Professor at the University of Texas School of Nursing, told the Commission that "if the family say they can't deal with this situation [a handicapped newborn], if they believe that their baby's life is going to be a life full of pain and suffering," the family should be able to withhold treatment from their child. *Id.* (Statement of Joy Penticuff, Ph.D) at 205. Dr. Warren also expressed the opinion that the decision to treat is one which the family must make. *Id.* (Statement of Mary Anne Warren, Ph.D) at 160.

The bias of the physicians also extends in the area of decision-making by affecting what the doctors tell the infant's parents. A Michigan doctor says that "The worst possible prognosis is often the only one presented." Turkel, *After Baby Doe,* 78 South. Med. J. 364 (1985). Thomas Elkins, Assistant Professor, Chief, Division of Gynecology, University of Michigan Medical School, and Doug Brown, Assistant

Professor, Harding Graduate School of Religion, in their recent article in *Issues in Law and Medicine*, stated, "In an new era of noninstitutionalization, increased educational opportunities and increased socialization, the medical literature describing physical, mental, and social prognosis data for Down syndrome and many other disabilities is often obsolete." Elkins and Brown, *An Approach to Down Syndrome in Light of Infant Doe*, 1 Issues in L. & Med. 419, 432 (1986). Further, they detail the frustration parents of Down's syndrome children often feel because doctors frequently fail to acknowledge and talk to the parents of the benefits which such a child can bring to the family, dwelling instead on the child's limitations. *Id.* at 433.

A 1985–86 article published in the *Journal of Law and Health* described the parents' role as largely passive. The information they receive supports the recommendation of the physician, and the consent given is based upon such biased information. Malone, *Medical Authority and Infanticide*, 1 J. of L. and Health 77, 98 (1985–86). Malone goes on to say: "While parents can influence what a doctor recommends depending on whether physicians perceive the parents as positive or negative toward the infant, they are seldom active decision- makers in a meaningful way." *Id.* at 98–99. This information makes it much more likely that a bias by physicians will have a profound effect on the treatment decision that is made for a newborn with a disability.

It is obvious that many health care professionals still feel that there are circumstances in which it is proper to deny medical care to children with disabilities. Overwhelmingly, these decisions appear to be based on the doctor's own opinion regarding the child's "quality of life" after treatment. Governmental action to protect these children from death is, therefore, amply justified and urgently needed.

Attitudes elicit behavior. If societal attitudes concerning people with mental disabilities were not negative, one would not expect the same type of societal and legal discrimination against them as has existed, including by way of discrimination in medical treatment.

Because attitudes elicit behavior, it is important to consider them. The professional literature that I have reviewed consists of surveys about physician attitudes. Not surprisingly, physician attitudes are not significantly different (as reported) from general societal attitudes, both now and historically.

There is, however, another aspect of attitudes—one that the Commission, like the professional community, has overlooked. It is the attitude of people with disabilities and their families.

If attitudes truly do elicit behavior, then the attitudes of people with disabilities and their families must be considered as the proper federal governmental behavior is shaped by the Commission, Congress, and the courts.

Orlansky and Heward's *Voices: Interviews with Handicapped People* (1981) are strong first-person testimony concerning the positive quality of life that people with severe to mild physical or mental disabilities can and do have. Turnbull and Turnbull's *Parents Speak Out* (1986) contains powerful first-person accounts of the strength that parents of children with mental, emotional, and physical disabilities draw from their unusual parenthood, always in the face of devaluing and discriminatory attitudes held by some physicians and other professionals. *No More Stares* (1982), a publication of the Disability Rights Education and Defense Fund, Inc., gives further testimony to the fact that a positive quality of life can derive solely from being disabled.

My wife, Ann P. Turnbull, a professor at the University of Kansas, and I have been troubled by the almost single-minded focus on the pathology in disability—on the pervasive attitude, held by physicians and other professionals, that disability automatically equates with nothing except burden. Yet, as parents of a child with low moderate mental retardation who have been obliged (by lack of services) to institutionalize him, who brought him home, who began school programs for him, who are seeing him through his P.L. 94–142 education, and who believe that he has contributed mightily to our development and to that of our other children and his friends, we know that there is a potent positive part of life with such a child.

Some researchers have been surprised by findings that parents and others report that the child's life has consisted of positive dimensions (Wikler, Wasow, and Hatfield, *Chronic Sorrow Revisited: Attitude of parents and professionals about adjustment to mental retardation*, 51 Am. J. of Orthopsychiatry 63 (1981)). These researchers even dismissed those feelings, sometimes in error (Wikler, Wasow, and Hatfield, *Seeking strengths in families of developmentally disabled children*, Social Work 313–15 (1983)) and sometimes as rationalization (Wasserman, *Identifying counseling needs of the siblings of mentally retarded* *children,* 61 Personnel & Guidance School J. 622 (1983)). Knowing of these developments, we have begun a line of research at the University of Kansas on the positive aspects of the life of the person with a disability.

Concerning the Commission's attention to medical discrimination and attitudes of physicians and my argument in favor of considering attitudes of people who have disabilities and their families, we obtained copies of letters sent by parents or relatives and individuals who themselves have disabilities to the Department of Health and Human Services, commenting on the 1983 proposed regulations under section 504. We were interested in the opinions of these three groups concerning whether they supported the regulations and the reasons cited for their support.

We coded 174 letters according to the criteria of type of respondent, reasons for supporting the regulations, and the inclusion of recommendations pertaining to providing parent support or adoption options. We found that 173 respondents unanimously supported the regulations, and the 1 remaining respondent did not express support or objection. The qualitative analysis of reasons for supporting the legislation resulted in the identification of eight categories. The category of insuring equal treatment for newborns with disabilities received the highest number of citations—70 percent of respondents.

Of particular interest to our discussion is the category of positive contributions. Thirty-five percent of the respondents identified at least one positive contribution that the person with a disability had made to others. We identified six types of positive contributions.

The most frequently mentioned type was the person with a disability being a source of joy to the family. This category was mentioned by 39 percent of those respondents who indicated a positive contribution. An example of this kind of positive contribution is as follows:

> I am a thirty-five year old parent of a sixteen month old child diagnosed as having Down Syndrome and a severe congenital heart defect. And yet, as imperfect as he may appear to many "professionals" and "intellectuals" of our day, I wouldn't trade him for any other child in this world. I cannot begin to sufficiently articulate the profound joy this child has brought into our lives. He may never grow up to be president of anything, but that surely doesn't mean that he does not contribute in a positive way. His life is so very precious us.

An equal number of respondents (28 percent) addressed the next three types of positive contributions. The first of these is a source of learning life's lessons. Many different types of lessons were mentioned, including "patience," "less self-centered," "greatness of character," and "worth and dignity of all individuals." A more complete description was provided by a mother on what her family had learned from her child with severe mental retardation:

> My life and the lives of my family were changed forever on January 18, 1980. At about 6:00 p.m. our daughter Sarah was born. She weighed three pounds. Her diagnosis from the doctors was hopeless, 24 hours to live, deaf, blind, severely retarded.
>
> As I looked at her, fighting to live, held her in the palm of my hands, amazed that this little one was my daughter, hope became eternal for me.
>
> For the next 26 months she taught us more about love, courage, faith and life than most of us could teach or learn in 100 years.

The next type, source of love, as also identified by 28 percent of the respondents. We coded comments in which the respondent described family members or friends being the primary beneficiary of the love. An example of such a comment is as follows:

> Anyone who feels that someone else is a burden has not learned to love. Love feels someone else's needs above their own. My son, Matthew, was not useless. . . .If he served no other purpose than to give me love, then he served that one and if he served to other purpose than to teach me love, he served that one.

The category, source of blessing or fulfillment, was the third type of positive contribution identified by 28 percent of the respondents. Key words mentioned in these passages were "blessing," "fulfillment," "cherish," "enriched," and "completeness." An example of this kind of positive contribution is:

> We are the parents of a brain-damaged son. Todd is now 20 years old and although we encountered some very stressful times during his early years, we believe very definitely that God allowed him to be born in our family. Although he is somewhat handicapped mentally he is. . .a blessing and encouragement to many (including us). I shudder to think that someone might have decided that he had no right to live.

The final two categories were identified by substantially fewer respondents—source of pride by 8 percent and source of strengthening family by 5 percent. A quote from one mother provides an illustration of both of these categories:

> My son and only child is thirty-four years of age and considered profoundly retarded. His presence has strengthened our family ties and he is a source of pride. Surely the lives of my husband and I would be barren indeed without him.

I respectfully request the Commission to accept into the record as evidence the complete set of letters that we obtained under the Freedom of Information Act.

These letters also revealed that, although the greatest percentage (70 percent) of the correspondents favored the section 504 regulations because of equal treatment concerns, the second (42 percent) greatest portion favored them because of the positive characteristics of the person with a disability, and the third (35 percent) greatest portion favored them because of the positive effects of the person on others. A loss of confidence in the medical profession was expressed by 30 percent of the writers, and inaccurate medical prediction was noted by 9 percent of them.

Along with others (A. Lipsky, *Parental Perspective on Stress and Coping,* 55 Am. J. Orthopsychiatry 614 (1985); A. Turnbull, Blue-Banning, Behr, Kerns, *Family Research and Intervention: A Value and Ethical Examination,* in Dokecki and Zaner (eds.) (1986), Ethics and Decision-Making for Persons with Severe Handicaps: Toward an Ethically Relevant Research Agenda, Baltimore: Paul H. Brookes Publishing), I believe that professionals and government agencies alike make serious errors in assuming that disability alone is horrific and burdensome for the person, families, and society. Surely disability can be a factor in a "poor quality of life." But quality of life is inversely related to public and professional attitudes and behavior. If the Commission is serious about the federal role in improving the quality of life of people with disabilities, their families, and the public, it had better recognize that the federal government has the power to change the discriminatory attitudes and behaviors, and that there is another side of attitudes, one that proclaims, that although a person is less able, that person is not less worthy of our protection, concern, and support.

Finally, I would like to reiterate and expand my comments on the parent-physician relationship and its role in the process of deciding whether to treat a newborn with a disability. The Supreme Court's *Bowen* decision posits a parent decision concerning treatment and from that predicate holds section 504 rules inapplicable to treatment/nontreatment decisions. The factual basis for the plurality opinion is seriously to be doubted.

Oftentimes, families' decisions concerning treatment will depend on how physicians approach the family, the child, and the "problem" of the child's disability. It is for this reason, among others, that parent-professional interactions and counseling have been thoroughly covered in the literature (see, e.g., K.L. Moses (1983), *The impact of initial diagnosis: Mobilizing family resources,* in J.A. Mulick and S.M. Pueschel (eds.), Parent-professional partnerships in developmental disability services, Cambridge: The Ware Press; S.M. Pueschel (1983), *Parental reactions and professional counselling at the birth of a handicapped child,* in J.A. Mulick and S.M. Peuschel (eds.), Parent-professional partnerships in developmental disabilities services, Cambridge: The Ware Press; E. Sassaman (1983), *The parent-physician decision-making team,* in J.A. Mulick and S.M. Peuschel (eds.), Parent-professional partnerships in developmental disabilities services, Cambridge: The Ware Press; B.Z. Friedlander, G.M. Sterritt, and S.G. Kirk (eds.) (1975), Exceptional infant—assessment and intervention, New York: Brunner/Mazel; L. Buscaglia (1975), The disabled and their parents: A counselling challenge, Thorofare, N.J.: Charles B. Slack; T.B. Brazelton, B. Koslowski, and M. Main (1974), *The origins of reciprocity: The early mother-infant interaction,* in M. Lewis and L. Rosenblum (eds.), The effect of the infant on its caregiver, New York: John Wiley & Sons). Indeed, physicians who themselves are parents of disabled children are especially sensitive and expert about this delicate relationship (G.H. Durham (1979), *What if you are the doctor?* in T. Dougan, L. Isbell, and P. Vyas (eds.), We have been there, Salt Lake City: Dougan, Isbell, and Vyas Associates; Pueschel (1983)), and one of them, Dr. S. Peuschel, is a pediatrician whose child is mentally retarded and is a member of the national advisory board for this research proposal. In addition, "how-to" literature abounds concerning effective techniques for physician-parent interaction, but much of it is written from the perspective of the physician (J. Howard (1982). *The role of the pediatrician with young exceptional children and their families,* 48 Exceptional Children 316–22; M.L. Wolraich (1982), *Communication between physicians and parents of handicapping children,* 48 Exceptional Children 324–29; A.L. Rubin and R.L. Rubin (1980), *The effects of physician counselling technique on parent reactions to mental retardation diagnosis,* 10 Child Psychiatry & Human Devel. 213–21; S.M. Peuschel and A. Murphy (1976), *Assessment of counselling practices at the birth of a child with Down's syndrome,* 81 Am. J. Mental Deficiency 325–30).

In fact, the scant research on the factors that physicians take into account when they meet with parents suggests that physicians mediate their advice according to factors that relate to the family, not the child (A.C. McDonald, K.L. Carson, D.J. Palmer, and T. Slay (1982), *Physicians' diagnostic information to parents of handicapped neonates,* 20 Mental Retardation 12–14; R.I. Clyman, S.H. Sniderman, R.A. Ballard, and R.S. Roth (1979), *What pediatricians say to mothers of sick newborns: An indirect evaluation of the counselling process,* 63 Pediatrics 719–23). In addition, it is almost certain that physicians do *not* disclose *all* of the information that parents need for the treatment/decision. I myself have experience with physicians withholding important treatment information (Turnbull, *Jay's Story,* in H. Turnbull and A. Turnbull (1986), Parents Speak Out, Columbus, Ohio: Charles E. Merrill Publishing Co.).

One of the witnesses before this Commission, Rosalyn Benjamin Darling, has written extensively concerning physician-parent relationships and raised questions about the thoroughness of disclosure, and therefore, about the information element of informed consent, in the newborntreatment decision (Darling, *Parent-Professional Interaction: The Roots of Misunderstanding,* in M. Seligman (ed.) (1983), The Family with a Handicapped Child: Understanding and Treatment, New York: Grune & Stratton, Inc.; Darling, *The Birth Defective Child and the Crisis of Parenthood: Redefining the Situation,* in Callahan and McCluskey (eds.) (1983), Life-Span Developmental Psychology, New York: Academic Press; Darling, *Parents, Physicians, and Spina Bifida,* Hastings Ctr. Rep., August 1977).

Harrison *(The Parents' Role in Ethical Decision Making,* 2 Support Lines 11–23 (1984)) reviewed the parents' role in decision-making and noted the following:

1. the decision to designate a particular case as one requiring parental participation in decision-making is itself a medical staff decision;
2. parents usually are presented by medical staff with only one option, under the theory that exposure to diverse views would lead to parental confusion and frustration;
3. parents are such "hostage(s) to circumstances" that, in one physician's view, parental choice is a misnomer, the staff managing the decision-making "absolutely";
4. physicians and other medical staff have such extensive power of persuasion that parental informed consent is a "farce";
5. physician opinion is shaped by physician attitudes and values, not just philosophical values but also scientific values of acquiring new knowledge by providing treatment that will be of little, if any, benefit;
6. physician opinion also is shaped by the prevailing legal climate, particularly one that causes physicians to practice defensive medicine;
7. physician opinion also is shaped by financial considerations, namely, the parents' third-parties' ability to pay for medical attention.

It is undisputed that the manner in which parents are informed by medical staff concerning the child and the treatment options has a distinct bearing on parents' decisions to consent or not consent to treatment (Shaw, Randolph, and Manard, *Ethical Issues in Pediatrics Surgery: A National Survey of Pediatricians and Pediatric Surgeons,* 60 Pediatrics 588 (1977); Clyman, Sniderman, Ballard, and Roth, *What Pediatricians Say to Mothers of Sick Newborns: An Indirect Evaluation of the Counselling Process,* 63 Pediatrics 719 (1979)).

Research studies have clearly demonstrated parents' need to receive honest and complete information about the child's condition and to have that information given on a continual basis (Drotar, Baskiewicz, Irvin, Kennel, and Klaus, *The Adaptation of Parents to the Birth of an Infant with a Congenital Malformation: A Hypothetical Model,* 56 Pediatrics 710 (1975); Solnit and Stark, *Nurturing and the Birth of a Defective Child,* 16 Psychoanalytic Study of the Child 523 (1961). It is ironic in the extreme, therefore, that some physicians assert that offering treatment alternatives to parents is dishonest because parents are highly influenced by physicians' opinions (Nolan-Haley, *Defective Children, Their Parents, and the Death Decision,* 4 J. Legal Med. 9 (1976)). Others even assert that the physician should be the sole decision-maker in order to relieve parents of guilt should the child die as a result of not treating it (Strong, *The Neonatologists' Duty to Patient and the Parents,* 14 Hastings Ctr. Rep. 10 (1984)).

There also is reason to believe that physicians' information and counselling is not value-neutral (Hauerwas, *The Demands and Limits of Care: Ethical Reflections on the Moral Dilemma of Neonatal Intensive Care*, 269 Am. J. Med. Sciences 222 (1975)) and that medical criteria should be, in any event, the major issue, not physician value judgments that can cloud the decision-making process (Duff and Campbell, *On Deciding the Care of Severely Handicapped or Dying Persons: With Particular Reference to Infants*, 57 Pediatrics 487 (1976); Fost, *Counselling Families Who Have a Child with a Severe Congenital Anomaly*, 67 Pediatrics 321 (1981)).

Appendix C

State by State Evaluation of Child Protective Services Agencies

Preface

This appendix contains an analysis of State CPS agency compliance with the Child Abuse Amendments (CAA) and their implementing regulation. The Commission examined each State's policy and procedures for investigation of reports of withholding of medically indicated treatment from infants with disabilities who have life-threatening conditions as of the third quarter in 1988. In carrying out this examination, Commission staff conducted telephone interviews with State CPS agency workers, reviewed additional material received from the States, and made use of information from a survey of the State agencies conducted in 1987 by the journal, *Issues in Law and Medicine*.

As a result, the following evaluations suffer from one very important caveat. With rare exceptions, they can examine only what might be called "paper compliance"—the degree to which written procedures appear to reflect the requirements of the relevant Federal regulation. A State could be in complete "paper compliance," yet in practice choose medical consultants hostile to the law they are in theory enforcing, defer unduly to the views of the physicians they are investigating, or give only cursory examination to reports. The Commission could detect such important failures of compliance only when other information shed unexpected light. (For an example of a State in paper compliance but which other information disclosed was substantially out of compliance, see the section on New Hampshire.)

For this reason, a conclusion contained in this appendix that a State appears on the face of its procedures to be in compliance with the CAA should not be cited as a definitive finding by the Commission that the State is in fact fully fulfilling its responsibilities to enforce the law.

In general, the compliance review contained in the following State by State analysis concentrates on certain key features. The number and disposition of relevant reports of medical neglect is recounted, and a comparative description of the extent to which the agency sought input in designing its procedures from representatives of the class the law was designed to protect (disability rights groups) and representatives of the class the law was intended to regulate (medical groups) is given. Central to the CAA, of course, is the standard of care required to be enforced. This is embodied in the definition of "withholding of medically indicated treatment," so the compliance review reports on the State's inclusion of a definition of this term that corresponds to that in the Federal regulation.

Of similar importance is delineation of the class protected by the standard of care, so the review reports on the adequacy of the State's definition of "infant." Vital to effective enforcement is the ability and readiness of the State agency to obtain access to medical records and to obtain court orders for independent medical examinations, so the State's compliance with Federal regulatory provisions relating to these is assessed. Perhaps most crucially of all, the compliance review assesses the degree to which the agency appears to equip itself with adequate independent medical advice in order to assess effectively whether legally required treatment is being provided, or, on the other hand, the extent to which it abdicates its duties by deferring to views expressed by committees at the institution whose staff is being investigated or even by the subject of the investigation herself or himself.

The following prefatory notes discuss the more common forms of failure to comply with Federal law.

NOTE A: CPS delegates to an ICRC the question of medical neglect. The Federal regulation is clear that it is the State's CPS system which must make the determination whether treatment is legally required because it meets the definition of medically indicated under the CAA. The existence of an infant care review committee (ICRC) has no bearing on a State CPS agency's duty to investigate all known or suspected cases of medical neglect and determine whether treatment of the child is required or whether one of the three treatment exceptions is applicable. Nor does the existence of an ICRC amend the duty of the hospital or medical professionals to notify the CPS of suspected or known instances of medical neglect. Moreover, the existence of an ICRC does not permit an abdication of the agency's duty to determine what circumstances exist to invoke the power of the State. Unwarranted agency reliance on ICRC views compromises the intent of the statute and places an agency out of compliance with the Child Abuse Amendments.

As shown in chapter 10, the statute and HHS' implementing regulation elucidate the separate and distinct roles of the ICRC and the CPS agency. HHS envisioned that the ICRC would, in effect "offer counsel to the attending physician(s), the hospital and the family to assure that the parents have the benefit of prudent, knowledgeable and professional evaluations, recommendations and services, consistent with appropriate medical standards, to assist them in making sound decisions regarding the welfare of their child. The CPS agency, on the other hand, represents the interests of the infant and must determine those circumstances in which the power of the State must be invoked to protect the infant, and then to take appropriate action to do so."[1]

NOTE B: CPS treats ICRCs as the independent medical examiner. Federal regulations require that State CPS agencies must have the ability to obtain "[a] court order for an independent medical examination of the infant,. . .when such access is necessary to assure an appropriate investigation for a report of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions)."[2] The term "independent" by definition denotes an individual free from the influence, guidance, or control of another. A hospital's ICRC does not qualify; it is not independent of the hospital, whose alleged neglect is presumably being investigated. To conduct truly independent examinations, a CPS agency must develop its own bank of independent consultants. Yet in some States, the CPS agency evidently regards the judgments of the ICRC as akin to an "independent medical examination." This practice subverts the intent of the CAA and their implementing regulation to construct an independent enforcement mechanism for the purpose of protecting the right to treatment of infants with disabilities.

NOTE C: CPS fails to provide for access to medical records. Federal regulations require that a CPS agency's investigative policies and procedures "must be in writing" and "must specify" the manner in which it will obtain "[a]ccess to medical records and/or other pertinent information when such access is necessary to assure an appropriate investigation of a report of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions). . . ."[3]

NOTE D: CPS fails to provide for obtaining court orders for independent medical examination of an infant. Federal regulations require that a CPS agency's investigative policies and procedures "must be in writing" and "must specify" the manner in which it will obtain "[a] court order for an independent medical examination of an infant or otherwise effect such an examination in accordance with processes established under State law when necessary to assure an appropriate resolution of a report of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life threatening conditions)."[4]

Concerning these sections of the regulation, HHS stated in its section-by-section analysis:

> We have added language to paragraph (c)(4) to require that as a part of the development of programs and/or procedures required in paragraph (c), the State child protective system must specify the procedures to be

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[1] *Services and Treatment for Disabled Infants, Model Guidelines for Health Care Providers to Establish Infant Care Review Committees,* 30 Fed. Reg. 14,901 (1985).

[2] *Id.*

[3] 45 C.F.R. §1340.15(c)(4)(i) (1987).

[4] 45 C.F.R. §1340(c)(4)(ii) (1987).

> followed, consistent with State law, to carry out these actions
>
> . . .These additions to paragraph (c)(4) of the final rule clarify that, in connection with this conformity requirement, the State's programs and/or procedures must make provision, consistent with State laws, for access to medical records and medical examinations when necessary. Although these actions will not be needed in every investigation of reported medical neglect, the specific identification of these procedures for use by agency staff increases the protections for disabled infants.[5]

NOTE E: CPS fails to provide adequate definition of the term "infant." Many CPS agencies have policies which either do not define the term "infant" or—in direct contravention of the governing regulation—define the term to encompass only infants of less than one year in age. The Child Abuse Amendments standard of medical treatment States that:

> The term "infant" means an infant less than one year of age. The reference to less than one year of age shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age. *In addition to their applicability to infants less than one year of age, the standards set forth. . .should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability.*[6]

Supplemental Information HHS published with the Final Rule explained the above definition by noting that, as a condition of receiving child abuse and neglect grants, States must have procedures that ensure the detailed standards in the CAA are thoroughly consulted with regard to certain categories of infants over 1 year of age.

> [A]s a general rule, issues of medical treatment for infants over one year of age are to be considered under the less precisely defined, but clearly applicable, standards of "medical neglect." Issues of medical treatment for disabled infants under one year of age with life-threatening conditions must be considered under the more precisely defined standards of the definition of "withholding of medically indicated treatment."
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> . . .[But f]or certain infants over one year of age, the Conference Committee believed the more precisely defined standards of the definition of "withholding of medically indicated treatment" might be more appropriate to use in considering the question of medical treatment than the more general standards of "medical neglect.". . .The apparent Congressional intent is to recognize that these three categories of infants, although over one year of age, share important characteristics with those infants under one year of age who are the principal focus of the statutory provision.[7]

It is noteworthy that the third category, those over 1 year of age who have "a long-term disability," is extremely broad. Thus, it is arguable that under the law the more precise standards should be consulted concerning medical treatment decisions for practically all children with disabilities, of whatever age.

NOTE F: CPS fails to provide an adequate definition of the term "withholding of medically indicated treatment." Many CPS agencies do not define medical neglect, or define it in such a way as to invite ambiguity. Properly defined, "withholding of medically indicated treatment" is:

> the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's (or physician's) reasonable medical judgment any of the following circumstances apply:
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> (i) The infant is chronically or and irreversibly comatose;
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> (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
>
> (iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment under the circumstances would be inhumane.[8]

This legal provision was scrupulously crafted by Congress to create narrow circumstances in which maximal treatment is not required.

Resort to "quality of life" considerations by any party are completely inconsistent with the law. HHS stated in its Final Rules that "[a] number of commenters argued that the interpretation should permit, as part of the evaluation of whether treatment would be inhumane, consideration of the infant's future

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[5] 45 Fed. Reg. 14,883 (1985).

[6] 45 C.F.R. §1340.15(b)(3)(i) (1987) (emphasis added).

[7] *Child Abuse and Neglect Prevention and Treatment Program*, 50 Fed. Reg. 14,878, 14,882 (1985).

[8] 45 C.F.R. §1340(b)(2) (1987).

'quality of life.' *The Department strongly believes such an interpretation would be inconsistent with the statute.*'[9] HHS has made clear that the focus is on the treatment itself and not on the nature or quality of child's life.

ALABAMA

In Alabama, the Division of Child Protective Services in the Bureau of Family and Children's Services of the Department of Pensions and Security is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In designing its approach to implementation, the division consulted with hospitals in the State; it could not name any disability groups that were invited to participate. In selecting physicians to serve as independent medical consultants, it used doctors designated by the Alabama chapter of the American Academy of Pediatrics.[10]

As of 1987, the agency stated that it had responded to two reports of medical neglect of infants with disabilities since 1985, when the regulations took effect. In 1988 the agency stated that it had received no reports in the last year.[11]

The State agency's procedures were reviewed for compliance with the Federal regulations that implement the CAA. The Alabama *Family and Children's Services Manual* sets forth the procedures required to be followed in investigating reports of child abuse and neglect. The manual defines "withholding of medically indicated treatment" and "reasonable medical judgment" in accordance with the Federal regulation. However, absent from the manual is any definition of "infant." Moreover, the introduction of the section concerning medical neglect of handicapped infants is entitled, "Reports of Medical Neglect of Handicapped Infants Under One Year of Age."[12] The absence of a definition of "persons protected by the CAA" and the incorrect limitation reflected in the title give the impression that the agency will only respond to reports of medical neglect to infants younger than 1 year old. Under this language, the agency would fail to protect a large group of infants within the group covered by the CAA.

In a letter dated October 7, 1988, the Assistant Attorney General and Legal Counsel for the Alabama Department of Human Resources responded on behalf of the agency to a draft of relevant portions of the Commission report. The State argued that because Alabama law provides that a child is anyone under the age of 18, the department would always investigate a report of medical neglect of any child regardless of age: "Those procedures go on to state that special procedures on handicapped infants under one year of age. . .are found in another section. Thus, the Department does investigate cases of medical neglect of handicapped infants and other children as well."[13]

The State's response did not recognize that the "special procedures" required under the CAA apply as well to handicapped infants past their first birthday. Although Alabama may assert that it investigates reports of medical neglect of infants older than 1 year, there is no indication in its procedures that it will apply to them the detailed standard of care the CAA creates for "disabled infants with life-threatening conditions." (For an elaboration of the requirements governing this area, see Preface, NOTE E.)

The procedures also fail to specify in writing the manner in which the CPS agency will obtain access to the medical records of a handicapped infant in the event that medically indicated treatment has allegedly been withheld. Surprisingly, in its response to the Commission's preliminary draft, the Assistant Attorney General for the State of Alabama stated: "There is no provision in the federal regulations requiring that the State plan or procedures outline in writing a procedure for obtaining medical records." The plain language of 45 C.F.R. § 1340.15(c)(4)(i) refutes this assertion. (See Preface, NOTE C.)

Most egregiously, the Alabama procedures manual explicitly abdicates to a hospital infant care review committee (ICRC) the authority to decide whether illegal denial of treatment is taking place, contrary to the requirements of the Federal regulation that the CPS must make the determination whether treatment is legally required under the CAA. The procedures provide: "In cases where there is agreement between the treating physician and the [ICRC],. . .the County Department will simply apprise the court having jurisdiction over juveniles of the case by submitting a written summary."[14] Independent medical opinion will be sought, according to the procedures, only in those cases in which there is no internal committee. The procedures state: "In counties where there are no Infant Care Review Committees nor multidisciplinary teams operational, the County Department must consult a local independent physician for a medical opinion on the case."[15] The flaw disclosed by this formulation is its failure to anticipate a circumstance in which the parents and the medical providers agree to withhold treatment—the typical situation that the CAA attempts to address. The foregoing language clearly allows the hospital that has had a complaint lodged against it to sit as a judge in its own case.

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[9] 45 C.F.R. pt. 1340 app. no. 9 (1987).

[10] Telephone interview with Mary Carswell, Bureau of Family and Children's Services, by *Issues in Law and Medicine* (June 10, 1987).

[11] *Id.* and telephone interview with Mary Carswell. Bureau of Family and Children's Services (July 28, 1988).

[12] Alabama Dept. of Pensions and Security, I Family and Children's Services Manual, at VII-53 (Rev. May 1988)

[13] Letter from James E. Long, Assistant Attorney General and Legal Counsel, Alabama Department of Human Resources, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 7, 1988).

In his response to the Commission, the Assistant Attorney General and Legal Counsel for the State of Alabama Department of Human Resources wrote:

> Alabama's procedures recognize that duly authorized ICRCs are made up of a broad range of medical professionals. If a duly authorized ICRC decides that treatment may be withheld, there is no difference of medical opinion which would support a court petition. As an attorney who has litigated these cases, I find your objection to Alabama's procedures puzzling. On what ground and with what evidence would the Commission propose to present to a court? If a duly constituted ICRC agrees with a course of action, there is nothing to present to a court. Of course, Alabama will review the report to determine if the ICRC adequately analyzes the case. However, the Alabama experience has been that a team determination by a group of medical professionals, absent proof of actual bias, will nearly always be given more weight than a nonmedical opinion or even an opinion by a lone independent physician.

Alabama's response reinforces the conclusion that the CPS has unlawfully abdicated authority to hospital ICRCs. Alabama's response does not appear to recognize that Federal law has vested the CPS agency with the duty of ensuring that the medical treatment standards under the CAA are being properly applied. It is well established that the existence of an infant care review committee in a hospital does not relieve a State child protective services agency of the responsibility to provide the objective third-party inquiry into suspected cases of withholding of medically indicated treatment. (See chapter 10.) Alabama would do well to obtain an independent medical consultant, not affiliated with the hospital, to assist the CPS in the investigation of a report of withholding of medically indicated treatment of an infant with a disability. (For an elaboration of the requirements governing these areas, see Preface, NOTES A and B).

Alabama presents a case of a State CPS agency that has wrongfully delegated to the hospital ICRCs the legal question whether there is a withholding of medically indicated treatment. In addition, the agency does not have in its procedures a definition of "infant" or a provision for access to medical records. It is fundamentally out of compliance with the CAA and its implementing regulation.

ALASKA

In Alaska, the Division of Family and Youth Services of the Department of Health and Social Services is the State agency responsible for compliance with and enforcement of the Child Abuse Amendments of 1984 (CAA).

In designing its approach to implementation, the division did not consult with either medical or disability groups.[16] After the policy had been in effect for a year, however, the agency wrote State health care facility directors expressing the hope that they found the agency's approach "to be of assistance with these unusual cases" and inviting their comment on any "areas of our policy which you feel are impediments to effective coordination in these cases."[17] There is no record of any similar inquiries made of disability groups.

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[14] *Id.*, para. 6.

[15] *Id.*, para. 1.

[16] Information provided to the Commission by *Issues in Law and Medicine* based upon a telephone interview with Dee Ann Grummett, Division of Family and Youth Services, on June 11, 1987.

Agency procedures identified by the agency as its written division policy and procedure[18] reprint verbatim the relevant sections of the CAA and its implementing regulations. A copy of this interim policy and procedure was provided to the Commission in August 1988 by the division when the Commission requested copies of current policies and procedures. In view of the interim policy's inclusion of relevant sections of the CAA and implementing regulations, it is surprising to find that the interim policy includes a definition of infant that is inconsistent with the Federal definition. The interim policy provides: "These policy [sic] and procedures relate only to handicapped infants under the age of one year in hospitals or other health care facility [sic]."[19] This limitation illegally excludes those infants over 1 year of age who meet the criteria set forth in the Federal regulations, as well as any child with a disability who might be in a health care facility. (See Preface, NOTE E.)

Asked to comment on this criticism, the agency provided the Commission with copies of agency policies that define infant in conformity with the CAA. The policies, both issued in April 1988, indicate that they were superseded by policies issued in June 1988 and October 1988. Neither of the superseding policies was provided to the Commission.

The Alaska procedures explicitly abdicate the State's responsibility to investigate reports in hospitals where there exists an infant care review committee (ICRC). The division summarizes its policies as follows:

> [F]ederal and state law require that medical providers report immediately to the Division of Family and Youth Services if they have reason to believe that medical treatment is being improperly withheld from a disabled infant. Division policy requires that once such a report is received, the complaint be immediately referred to the medical facility's review board, if one exists, for a determination as to whether or not the complaint is valid. If a committee does not exist within the facility, Division policy provides that this agency will assist the medical facility in arranging for an independent medical examination of the alleged victim. If the evaluation by the review board or independent evaluator indicates that medical treatment is being improperly withheld, the Division would proceed as in any case requiring protective action for a child in danger of harm by filing a petition with the court.[20]

The State regulations provide, "*Consensus of the [Internal Review] Board that Treatment is Appropriate.* Upon notification to the [agency] worker that treatment is appropriate in relation to criteria outlined in the Federal regulations cited under (a)(2) of this section, the worker shall close the case."[21] When the infant care review committee fails to achieve consensus, "the worker *shall assist the board* in arranging for an independent medical examination of the infant."[22] If a facility has no internal review board, "the worker receiving the complaint will immediately contact the designated personnel at the facility and request assistance and cooperation in arranging for an independent medical evaluation of the infant."[23]

In other words, the agency worker is to ask those charged with discriminatory denial of treatment to name the "independent" individual who is to rule on whether of not what they are doing is proper. Thus, whether or not a health care facility has a review committee, the Alaska agency seems to believe that it exists to rubber stamp the practices of hospitals that are the subject of a denial to treatment report rather than investigate them. (See Preface, NOTES A and B.)

In response to an inquiry, an agency representative stated that there had been no cases reported to the agency since the regulations went into effect.[24] In a update inquiry this year, the division manager reported that she had not heard of any reports of withholding of medically indicated treatment.[25]

Alaska presents a case of a State CPS agency that has wrongfully delegated to the hospital ICRC's the legal question whether there is a discriminatory withholding of medical treatment to a disabled infant. In so doing, the agency has distorted the CAA's intent to create a strong enforcement mechanism for the treatment of disabled children and should be regarded as in violation of Federal law.

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[17] Letter from Michael L. Price, Director, Division of Family and Youth Services, to Health Care Facility Directors (Oct. 6, 1986).

[18] Report of Harm Regarding Medical Neglect of Handicapped Infants in Hospitals and Health Care Facilities, §300.05.045, cited in Division of Family and Youth Services documents provided to the U.S. Department of Health and Human Services by cover letter dated Oct. 15, 1985, from Michael L. Price, Director.

[19] *Id.* at §5.045(b).

[20] Letter to Health Care Facility Directors from Michael L. Price, Director, Division of Family and Youth Services (Oct. 6, 1986).

[21] Alaska Admin. Code tit. 300, § 5.045(c)(B)(iii) (January 1987)

[22] *Id.*, § 5.045(c)(1)(B)(i). Emphasis added.

[23] *Id.*, § 5.045(c)(2)(A).

[24] Telephone interview with Dee Ann Grummett, Division of Family and Youth Services, by Andrew Sondag (June 11, 1987).

[25] Telephone interview with Martha Holmberg, Manager, Division of Family and Youth Services, by Vincent Mulloy (Aug. 1, 1988).

ARIZONA

In Arizona, the Administration for Children, Youth and Families of the Arizona Department of Economic Security is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In 1987 the Arizona CPS reported that it had received only one report alleging denial of medical treatment to an infant with a disability since enactment of the CAA. In describing that situation, the agency stated:

> We have had one CPS report that was classified as "Baby Doe." A petition was filed with the Juvenile Court to monitor the child's treatment. When it was determined that further treatment would do no more than temporarily prolong the act of dying the court dismissed the petition and the child died a natural death while hospitalized.[26]

In an update, a representative of the agency stated that it had received no reports in the past year.[27] The agency has reported that medical associations were consulted in the preparation of its policies and procedures for medical neglect situations but that no disability rights groups were consulted.[28]

Although the procedures of the Arizona CPS incorporate by reference the Federal regulation implementing the CAA, they contain language that is ambiguous or inconsistent with the regulation. The CPS definition of "medically indicated treatment," which establishes the standard of care, differs from that in the Federal regulation. Thus, it states not only that treatment would not be mandated where it would be "futile or would do more than temporarily prolong the act of dying when death is imminent," but also that treatment would not be mandated "in circumstances where it is not necessary to save the life of the infant, [or] the potential risk to the infant's life or health outweighs the potential benefit to the infant of the treatment or care. . . ."[29]

The term "potential risk to the infant's life. . .outweighs the potential benefit" is ambiguous enough to allow a judgment that because of disability the child's quality of life would be so poor that lifesaving treatment would not be of "benefit" to the child. "Quality of life" considerations are inconsistent with the statute. (See Preface, NOTE F.)[30]

The policy directive also states that infant "means a newborn child less than one year of age."[31] The scope of this definition fails to include a large group of infants protected by Federal law. (See Preface, NOTE E.)

In at least some cases, the Arizona CPS has explicitly abdicated to hospital ICRCs the authority to decide whether illegal denial of treatment is taking place, contrary to the requirements of the Federal regulation. (See Preface, NOTE A.) When the hospital concerning which a report has been received has an ICRC, the policy states the Arizona CPS will file a dependency petition "if unresolvable disagreement exists between the parent(s)' or guardian(s)' plan to not provide nourishment or necessary medical treatment or surgical care for the child(ren) and recommendation of the hospital ICRC. . . ."

In the absence of a hospital ICRC, it further states, the CPS will file a dependency petition when disagreement exists between the parents or guardians, or physician, or "specialized medical consultation." These two types of situations do not include circumstances in which the parents and the medical providers wrongfully agree to withhold treatment—the very situation that the CAA were primarily intended to remedy. The clear implication is that the CPS will usually act only when there is disagreement among the parties named in section E. The procedures do provide for the filing of a petition "under circumstances other [than those listed aboved], including when medical records are not available on request, after decisionmaking process including the child protective services supervisor, and advice and counsel from an Assistant Attorney

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[26] Letter from Carol Ann Erikson, CPS Specialist, Administration for Children, Youth and Families, to *Issues in Law and Medicine* (May 20, 1987).

[27] Telephone interview with Beth Rosenberg, Manager, Policy Unit, Administration for Children, Youth and Families (July 28, 1988).

[28] Telephone interview with Carol Ann Erikson, CPS Specialist, Administration for Children, Youth and Families (June 24, 1987).

[29] Arizona Department of Economic Security Instruction 5-55-08.A (1988).

[30] A State statutory provision prohibits depriving "a newborn child of food, nutrients, water or oxygen. . .for any reason including. . .a handicap which, in the opinion of the parent or parents of the child, the physician or another person, diminishes the quality of the child's life." Ariz. Rev. Stat. § 36-2281(A).

[31] *Id.*

General."[32] However, the CPS evidently regards intervention in these circumstances as the exception rather than the rule, a conclusion reinforced by its letter commenting on a draft of relevant portions of the Commission report: "Policy. . .provides clear direction concerning use of the agency's legal authority, which is to petition the Juvenile Court in cases of specified disagreement as to treatment of the child."[33]

The State denied that its policy constitutes an "abdication to the ICRC" because "specialized medical consultation. . .is obtained as appropriate to the reports and investigations."[34]

Although the agency's policies do provide for the availability of such consultation, nothing in the letter of comment or the Arizona procedures negates the disturbing indication that the CPS agency regards the typical cases for its efforts to obtain a court order to be those in which there is disagreement between the hospital ICRC or a physician, on the one hand, and the parents, on the other, as opposed to cases in which legally mandated standards of treatment are being violated with the involvement of medical providers, the sort of situation that prompted enactment of the CAA.

Taking into account its inappropriate definition of the standard of care and the class protected, and its improper deference to committees of the very hospitals where staff would be the subject of reports of medical neglect, Arizona is out of compliance with the CAA and its implementing regulation. In so doing, the agency has distorted the CAA's intent to create a strong enforcement mechanism for the treatment of disabled children.

ARKANSAS

The Arkansas Division of Children and Family Services in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated on two occasions that there have been no reports of denial of medical treatment to infants with disabilities.[35]

The State agency's policies and procedures were reviewed for compliance with the Federal regulation that implements the CAA. The procedures do not specify the manner in which the agency will obtain access to medical records or a court order for an independent medical examination, contrary to the requirements of the Federal regulation.[36] The policy merely instructs the county CPS officer to contact the State office for guidance on the investigation. The procedures do not state the manner in which the investigation will proceed.

Arkansas properly describes the standard of care and the class protected by it as required by the Federal regulations.

In a telephone interview, the CPS staff manager stated that the agency's regulations were developed with the assistance of Arkansas Children's Hospital and that no disability groups were consulted. The manager also stated that the independent medical examiner for an investigation of medical neglect has been designated by Arkansas Children's Hospital.[37]

According to a letter from a State CPS administrator to HHS, Arkansas Children's Hospital "handles 90 to 95 percent of all 'Baby Doe' cases in the entire State."[38] In other words, the hospital that is most frequently under investigation for medical neglect was permitted to write the rules of investigation and to name the "independent" medical authority who will provide crucial medical assessments that will serve as the basis for the CPS determination whether a course of treatment or nontreatment is proper.

The CPS manager confirmed that a video had been made and was used in the training of State CPS personnel on the issue of medical neglect.[39] "Ethical Issues in the Medical Care of Infants and Children"[40] contains much discussion of medical ethics, but nowhere does it include any mention of Federal law regarding the denial of medical treatment.

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[32] *Id.*, §5-55-08.E(3).

[33] Letter from Darwin J. Cox, Program Administrator, Arizona Administration for Children, Youth and Families, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 11, 1988).

[34] *Id.*

[35] Telephone interview with Sandra Haden, Staff Manager, Child Protective Services, by *Issues in Law and Medicine* (June 12, 1987); telephone interview with Jeanette Lewis, Manager, Child Protective Services, by Commission staff (Aug. 1, 1988).

[36] The agency does have the authority to obtain a court order for an examination under Rule 35, ARCP. It also possesses subpoena power for the production of medical records under Rule 45, ARCP. However, 45 C.F.R. §1340.15(c)(4) (1987) requires that the agency specify in writing the procedures it will follow to exercise this authority.

[37] Telephone interview with Sandra Haden, Staff Manager, Child Protective Services, by *Issues in Law and Medicine* (June 12, 1987.

[38] Letter from Bobbie Fergusen, Acting Administrator, Child Protective Services, to Tommy Sullivan, Regional Director, Health and Human Services (Apr. 10, 1986).

[39] *Id.*

[40] On file with the U.S. Commission on Civil Rights.

The Arkansas CPS agency appears to have abdicated large portions of its duties under the CAA to the hospital whose treatment practices it has responsibility for investigating. It must be regarded as substantially out of compliance with the CAA and its implementing regulation.

COLORADO

The Colorado Division of Family and Children Services in the Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that there have been no reports of withholding of medically indicated treatment since the regulation went into effect.[41]

The agency's procedures were reviewed for consistency with the requirements of the CAA. Definitions for "withholding of medically indicated treatment," establishing the standard of care, and "infant," describing the class protected, accurately restate the Federal standards. As required by the Federal rule, the procedures provide for obtaining medical records.[42]

The agency has made explicit in its procedures the method to be used to obtain a court order for an independent medical examination to evaluate a specific charge of neglect (see Preface, NOTE D).

Absent from the procedures is any provision for an independent medical consultant to be available to review all reports of medical neglect. Such a consultant would be necessary to help the CPS investigator to do the examination, review the medical records, or otherwise assist the CPS worker. If the medically untrained CPS worker is unassisted in determining whether the health care facility is providing appropriate treatment, the CPS must rely solely upon the medical information received from the hospital against which the complaint was lodged.

The agency notes that "hospital review committees" exist in some hospitals "to deal with medical and ethical dilemmas."[43] A pamphlet produced for the agency by the University of Colorado Health Sciences Center with HHS funding discusses these committees. Although the pamphlet states that an infant care review committee is "not a decision making body," it then says, "It is hoped that the difficult decisions regarding medical treatment will be made here. If dispute about treatment persists, the state may need to step in."[44]

The two statements appear contradictory and could indicate a subordination of CPS authority to the infant bioethics committee (IBC). Moreover, the pamphlet implies that the CPS will take a passive approach to the enforcement of the CAA if it intends to step in only when there is a dispute with the IBC. It bears repeating that the CAA are intended to respond to a circumstance in which both the parents and the medical provider agreed to withhold medically indicated treatment, food or water from an infant with disabilities. The pamphlet indicates that the agency may not be particularly zealous in its responsibilities to the child.

In most respects the procedures in effect in Colorado are in substantial compliance with the CAA. However, the effectiveness of any investigation would be substantially improved were the agency to provide for the use of an independent third-party medical consultant, selected with input from disability groups, to assist the CPS worker in all nonfrivolous cases. In addition, explicit provisions for a court order for an independent medical examination should be added to the agency's procedures manual to clarify the investigatory process.

CONNECTICUT

The Connecticut Department of Children and Youth Services (CYS) is the State agency responsible for compliance with and enforcement of the Child Abuse Amendments of 1984 (CAA).

There have been no reports of medical neglect of infants with disabilities in Connecticut since the implementation of the CAA.[45] In response to an update conducted by the Commission, the agency stated that there had been no cases reported since its policy went into effect.[46]

Pediatricians, neonatologists, and disability groups were part of a task force that determined State policy on medical neglect.[47] This State policy is reflected in a joint agreement between CYS and the Connecticut Department of Health Services (DHS).[48]

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[41] Telephone interview with Janet Motz, Child Protection Administrator, Department of Social Services (Aug. 25, 1988).

[42] Colorado Department of Social Services, Staff Manual Volume 7, Social Services, Program Area V, Section 7.501.86.

[43] *Id.*, sec. 7.501.81(E).

[44] Medical Neglect and Disabled Infants, Responsibilities of the Medical Profession.

[45] Telephone interview with Linnea Loin, State Liaison Officer, CYS by *Issues in Law and Medicine* (May 4, 1987).

[46] Telephone interview with Linnea Loin, Program Supervisor, Department of Children and Youth Services (Aug. 3, 1988).

The agreement was based on: "[T]he need to clarify and define the functions of the [DHS] and [CYS] with regard to coordination and consultation with health care facilities providing inpatient newborn care and response to reports of medical neglect. . . ."[49] The agreement states that DHS will review policies on critically ill newborns, identify contact persons in health care facilities, maintain an ongoing dialogue with CYS on the handling of complaints of medical neglect, and "promote the establishment of Infant Care Review Committees in health care facilities with newborn units."[50]

CYS is responsible for investigating complaints of medical neglect upon order of the CYS chairman. Reports are to be received from a toll-free 24-hour "careline" established under the agreement. Health care facilities with newborn units were informed by CYS that they were required by law to report all cases of medical neglect. The investigative team consists of agency staff and a CYS-designated neonatologist from a hospital other than the one being investigated. The team is to make findings according to 45 C.F.R. §1340.15, inform parents and physicians, and forward its report to the CYS regional office. If there is a determination of medical neglect, CYS is to petition the court for custody so that treatment can be provided.

On its face, this joint policy appears to provide an objective investigation of reports that Federal standards of care for disabled infants are being violated. Its deficiencies lie in the absence of terms specifying the manner in which CYS will obtain "access to medical records and/or other pertinent information" or "a court order for an independent medical examination of the infant." (See Preface, NOTES C and D.)

In a letter dated October 11, 1988, the agency responded to a preliminary draft of relevant portions of the Commission's report. Documents submitted with their response did not demonstrate that its procedures explicitly provide for obtaining medical records or a court order for an independent medical examination as required by 45 C.F.R. §1340.15(4)(i) and (ii) (1987).

The agency did not directly respond to the Commission's assertion that the agency lacks a written policy specifying, pursuant to 45 C.F.R. §1340.15(4)(i)(1987), the manner in which it would obtain medical records to investigate a report of medical neglect. Rather, it argued that a CYS investigator's discretion to obtain court orders to remove the children whose welfare is threatened fulfills the requirement of the regulation at issue:

> The DCYS Policy Manual Volume 2, Chapter II Section 246.5 provides emergency guidelines whereby an investigator may remove a child without parental consent from dangerous surroundings. The criteria for emergency removal include reference to "caretaker(s) who refuse to permit the child to receive immediate medical care or to comply with on-going treatment recommended by a physician who examines such child."
>
> Section 244 of the same Policy Manual, provides for placement options for children in danger. No. 2, *Order of Temporary Custody—Superior Court—Juvenile Matters* provides for "a court order to safeguard the immediate welfare of a child which may be issued without a hearing and vests the care and custody of the child concerned in the. . .agency. . .pending the adjudication on the merits of Petition of Alleged Neglect."[51]

This information appears inadequate to fulfill the plain language of the Federal regulation, which requires that agency programs or procedures "must be in writing" and "must specify the procedures the state agency will follow to obtain. . .medical records."[52]

With regard to the requirement of a written policy providing procedures to obtain a court order to secure an independent medical examination, the agency cited §46b-121 of Connecticut General Statutes, which empowers the juvenile court to make and enforce orders protecting juveniles, and a 1985 State attorney general opinion attesting to the sufficiency of the agency's policies:

> Section 46b-121 of Connecticut's General Statutes, in defining the authority of the juvenile court, states in

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[47] Telephone interview with Robert Gossart by *Issues in Law and Medicine* (June 2, 1987).

[48] Telephone interview with Linnea Loin, State Liaison Officer, CYS by *Issues in Law and Medicine* (May 4, 1987).

[49] Agreement Between The Connecticut Department of Health Services and the Connecticut Department of Children and Youth Services Regarding Medical Neglect of Infants in Connecticut Health Care Facilities, Oct. 9, 1985.

[50] *Id.*

[51] Letter from Patricia Wilson-Coker, Acting Director, Children's Protective Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 11, 1988).

[52] 45 C.F.R. §1340.15(c)(4) (1987).

pertinent part: "In such juvenile matters, the superior court shall have authority to make and enforce such orders directed to parents. . .custodians or other adult persons owing some legal duty to a child or youth therein, as it deems necessary or appropriate to secure the welfare, protection, proper care and suitable support of a child or youth subject to its jurisdiction. . . ."[53]

This fails to meet the requirements of the Federal regulation. It is too broad in scope even to suggest to a CPS worker that an independent medical examination would be in order.

In some respects, the procedures in effect in Connecticut are in compliance with the CAA. However, the agency has failed to specify the manner in which it will obtain medical records or a court order for an independent medical examination of an infant in the manner required by Federal regulations.

DELAWARE

In Delaware, the Division of Child Protective Services in the Department of Services for Children, Youth and Their Families is the agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that it had not received any reports of possible withholding of medical treatment from disabled infants with life-threatening conditions.[54]

According to the agency, "medical personnel were necessarily involved in developing procedures in order to insure any reports would be made to our department."[55] However, there is no record that disability rights groups were consulted in the formulation of State policy for medical neglect cases.

Agency procedures were reviewed to determine consistency with Federal law. The definition of withholding of medically indicated treatment complies with the Federal regulation. However, there is no definition of "infant." (See Preface, NOTE E.)

The procedures abdicate the first portion of a medical neglect investigation to the hospital's "contact person." The procedures state that upon a receipt of a report, the CPS worker should immediately talk to the hospital's contact person to begin an inquiry. The contact person is to ascertain names of the parties, the status of the child's medical condition, and "whether the child's condition and treatment fall under the stated definition" of withholding of medically indicated treatment.[56]

"If the information received [from the contact person] indicates that the report does not come within the definition of medical neglect of handicapped infants, [further] procedures are not applicable in this case."[57] In effect, CPS will rely on the judgment of a contact person at the very hospital whose staff is allegedly denying legally required treatment to make an initial determination whether the allegation should be further investigated. This practice is contrary to the intent of Federal law that vests the CPS agency with the responsibility of determining whether treatment of an infant is legally required under the CAA. (See Preface, NOTE A.)

If the information provided by the contact person indicates that the case falls within the definition of medical neglect, CPS will contact the parents and consult with the hospital's PC/ICR. The latter individual is preselected "by the hospital with the agreement of the Division of Child Protective Services."[58] The CPS worker will rely on the judgment of this PC/ICR that the parents, the treating physician, and the hospital ethics committee (if one exists) are pursuing the proper course of treatment. Further, "if the parents and/or physicians have already obtained the PC/ICR's consultation and treatment is considered consistent with recommendations, the referral is deemed to be an 'unfounded' report of medical neglect."[59]

This approach gives rise to an an obvious conflict of interest: the entity being investigated has a key role in designating the physician who will sit in judgment on the case.

The CPS authority to make a determination of medical neglect is further diminished by an agreement between the Delaware Division of Public Health (DPH) and the CPS to investigate "jointly" complaints of "improper medical or nutritional care being delivered to handicapped newborn infants."[60]

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[53] Letter from Patricia Wilson-Coker, Acting Director, Children's Protective Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 11, 1988).

[54] Telephone interview with Robert Lindekamp, Coordinator, Division of Child Protective Services (Aug. 19, 1988).

[55] Letter from Kate Lorenz, Planner I, Department of Services for Children, Youth and Their Families, to *Issues in Law and Medicine* (June 18, 1987).

[56] *Medical Neglect of Handicapped Infants, Procedures,* at 2.

[57] *Id.*

[58] *Id.*, Attachment "B."

[59] *Id.*

[60] Memorandum of Understanding for Responding to Complaints of Improper Medical or Nutritional Care Being Delivered to Handicapped Newborn Infants Between the Division of Public Health, Department of Health and Human Services, and the

This agreement was signed and dated by the parties in October 1985. No reference to this agreement is made in the CPS procedures. According to the terms of the agreement, the DPH will "[a]pply the guidelines of the Bioethics Committee of the American Academy of Pediatrics in evaluating the medical aspects of the case in question" and the CPS will "[r]eview the case for violation of State Law, rules or regulations or Federal regulations."[61] Both "will jointly file a report with the respective Division Directors for further action."

In addition to failure to define the class protected by the CAA treatment standards, Delaware's CPS agency has diminished its authority by agreeing to conduct investigations jointly with other State agencies that are not obliged to enforce Federal standards and that are in fact applying antithetical standards. Most important, it has abdicated the crucial aspects of a medical neglect investigation to the agent of the hospital that is the subject of the investigation or to a physician chosen by that hospital. Delaware is significantly out of compliance with the CAA and its implementing regulation.

DISTRICT OF COLUMBIA

In the District of Columbia, the Child and Family Services Division in the Family Services Administration within the Department of Human Services is the agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that it had not received any reports of medical neglect of an infant with a disability. An administrator wrote: "There have been no referrals in the District of Columbia of cases in which a handicapped infant with life-threatening conditions has been denied medical treatment. However, we are aware of cases which have been resolved by the hospital and the parents without intervention from Child and Family Services."[62] In response to a followup inquiry, the agency confirmed that there had been no reports. An administrator stated that the hospitals' infant care review committees generally meet with the parents and the case is resolved at that level.[63] Thus, these cases are not reported beyond the institution and the CPS does not appear interested in becoming involved in them.

The agency reported that when it developed policies to implement the CAA, it consulted with a team of 47 health care professionals over a period of 5 months, contracting with the Children's National Hospital to coordinate the group. In addition, it stated that the procedures were reviewed by every major hospital organization and the American Bar Association.[64] An additional source wrote: "The draft procedure was reviewed by representatives from the Child Advocacy Center, Superior Court, the Metropolitan Police Department, St. Elizabeth's Hospital, the American Bar Association and all of the hospitals in the District of Columbia."[65] Noteworthy is the absence of any disability rights group.

The procedures were reviewed for consistency with the Federal regulation implementing the CAA. The standard of care established by the procedures contains an exception to the general requirement of maximal treatment that is not provided for in the Federal regulation: "if the treatment is part of an experimental research protocol."[66] However, supplementary information published with the Federal regulation does state:

> Nothing in the statute or rule forces use of experimental procedures. To the contrary, medical ethics, federal regulations, and many State laws require that patients (or their parents) provide "informed consent" based on free choice and without coercion when physicians propose human experimentation. These rules do not require such experimentation.[67]

Because the class protected by the standard of care includes all children,[68] and "child" is defined as "a person under 18 years of age,"[69] the standard covers a class that includes and is larger than that

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Division of Child Protective Services, Department of Services for Children, Youth and Their Families (October 1985).

[61] *Id.* See chap. 2 for a description of the significant differences between the American Academy of Pediatric guidelines and those in the Federal regulation.

[62] Letter from Dorothy Kennison, Adminstrator, Family Services Administration, to *Issues in Law and Medicine* (Apr. 10, 1987).

[63] Telephone interview with Carolyn Smith, Chief of Intake for Protective Services (Aug. 9, 1988).

[64] Telephone interview with Carolyn Smith, Chief of Intake for Protective Services, by *Issues in Law and Medicine* (June 15, 1987).

[65] Letter from Dorothy Kennison, Administrator, Family Services Administration, to *Issues in Law and Medicine* (Apr. 10, 1987).

[66] Department of Human Services Policy and Procedure, pt. IX, ch. 1, sec. C, topic 5 (I)(e)(ii) at 11 (date indeterminate).

[67] *Child Abuse and Neglect Prevention and Treatment Program*, 50 Fed. Reg. 14,878, 14,886 (1985).

[68] *Id.*

[69] *Id.*, (E)(6) at 3.

required to be protected under the Federal regulation.

In accord with the Federal regulation, the procedures specify the manner in which the department will obtain access to hospital records and obtain court orders for independent medical examinations and treatment. In addition, agency procedures present a detailed method for investigation by an independent medical consultant. The procedures indicate that the decision whether there exists an illegal withholding of medical treatment is vested in the department's medical officer with the assistance of the consultant:

> (2) When the allegation concerns a child in immediate danger from medical neglect in a medical facility,
>
> . . . .
>
> (e) Consult with the DHS Commission on Social Services medical officer. . .to ascertain, based on the information obtained:
>
> (i) Whether there has been a withholding of appropriate nutrition, hydration, and medication from the child;
>
> (ii) Whether there has been a withholding of treatment which in his or her reasonable medical judgment will be most likely to be effective in ameliorating or correcting all of the child's life-threatening conditions. Treatment is not medically indicated if the child is chronically and irreversibly comatose; if the treatment would merely prolong the child's dying or not be effective in ameliorating or correcting all of the child's life-threatening conditions, or would otherwise be futile in terms of the child's survival; would be virtually futile and the treatment itself under such circumstances would be inhumane; or if the treatment is part of an experimental research protocol;. . . .[70]

The District of Columbia presents a case of a CPS agency that has established investigative and enforcement procedures that meet the requirements of the CAA. However, it appears that the staff regards the hospital's ICRC as the appropriate forum to resolve the cases and does not seem interested in having these cases reported to them.

FLORIDA

The Children, Youth and Family Services Unit in the Florida Department of Health and Rehabilitative Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In designing its approach to implementation of the regulations underlying the CAA, the agency reported that it had consulted medical groups but not disability groups.[71]

In 1987 an agency staff person stated that there had been a rumor of a case of medical neglect, but no report to the agency.[72] In an update in 1988, a staff person stated that he knew of only one case in the last year. An attorney in Tampa called to report a case, but it was "handled appropriately by the hospital." He added that he "suspect[s] that cases of disabled infants are occurring in the State of Florida, but that the hospitals are handling the situations appropriately—which is the best of all worlds, really."[73]

Commission staff examined the agency's policies and procedures for consistency with the CAA and their implementing regulation. These procedures explicitly abdicate to the hospital the agency's responsibilities under Federal law to investigate and enforce the CAA. The procedures state that upon receipt of a report of medical neglect of a disabled infant, the CPS worker must contact the hospital "liaison" and that if this person reports that the treatment is proper "there is no need for further investigation."[74] If an infant care review committee (ICRC) exists at the hospital, the procedures state that the liaison person will arrange for it to meet and inform the CPS of the results of the meeting. The hospital's own ICRC reviews the case, and the liaison person will instruct the CPS, "based on [ICRC] response, whether there is reason for you to proceed further with provision of treatment for the infant."[75] When there is no ICRC at the hospital, the procedures direct that:

> The hospital liaison will inform you whether an independent medical examination is required to reach a conclusion or to protect the interest of the child. If such an examination is required, that liaison, if qualified, will

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[70] Department of Human Services, Policy and Procedure, pt. IX, ch. 1, sec. C, topic 5, at 10.

[71] Telephone interview with C. Christmas, Senior Human Services Specialist, Children, Youth and Family Services, by *Issues in Law and Medicine* (June 6, 1987).

[72] *Id.*

[73] Telephone interview with Chris Christmas, Senior Human Services Specialist, Children, Youth and Family Services (July 25, 1988).

[74] Florida Health and Rehabilitative Services Pamphlet 175-1, Special Procedures Relating to Medical Neglect of a Disabled Infant, §3.4.17.5.

[75] *Id.*, §3.17.7(1)(b).

conduct the examination or will assist you by finding the appropriate physician to conduct the examination."[76]

In the event that there is a question whether the hospital is in compliance with the law, the policy states that "[s]ince there are so many medical decisions involved, [the hospital liaison] will carry the primary responsibility for conducting the investigation."[77]

In a letter dated September 30, 1988, the agency responded to a preliminary draft of relevant portions of this report. The director of Children, Youth and Family Services in the Florida Department of Human Resources submitted the agency policy, quoted from above, for the position that "Health and Rehabilitative Services Pamphlet 175-1 dated July 1, 1988, specifically requires that CPS staff respond to reports of known or suspected abuse or neglect immediately or within 24 hours." This did not address the criticism in the portion of the report sent to the agency, which stated that on its face the policy explicitly abdicates to internal hospital infant care review committees or hospital staffs the authority to decide whether illegal denial of treatment is taking place when a report of suspected denial of treatment is received by the State agency.

The Florida CPS procedures do not provide for an independent medical review of a report of withholding of medical treatment from a disabled infant. The procedures establishing this review system present real conflicts of interest and present fundamental questions regarding the degree of protection given vulnerable children. (See Preface, NOTES A and B.) The procedures contain no provision for obtaining a court order for an independent medical examination. (See Preface, NOTE D).

In addition, in apparent response to the Commission's draft report, the director asserted that the "Child Protective Investigator's Decision Handbook further delineates the responsibility of the protective investigator to obtain a court order for treatment, if necessary." No documentation was provided for this assertion, and the fact remains that the current procedure lacks a specific provision, as required by the Federal regulation, that states the method the CPS agency will use to obtain a court order for an independent medical examination in a Baby Doe situation.

Florida presents the paradigm case of a State CPS agency that has wrongfully delegated its investigative responsibility to the very hospitals whose staff are the subject of alleged illegal denial of treatment.

GEORGIA

In Georgia, the Division of Family and Children Services in the Department of Human Resources is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The State CPS office stated that it was not aware of any cases of medical neglect in Georgia. The representative added that this "was left to the local authorities."[78]

The agency reported that it had consulted members of the State's infant care review committees in formulating its procedures for investigating of a report of withholding medical treatment from a disabled infant. No other associations, such as disability rights groups, were consulted.[79]

The State agency's procedures were reviewed for compliance with the Federal regulation that implements the CAA. The Georgia procedure does not specify in writing the manner in which it will obtain medical records (see Preface, NOTE C) or the manner in which it will obtain a court order for an independent medical examination of the infant (see Preface, NOTE D).

Most seriously, the agency procedure codifies an abdication of its responsibility to conduct an independent agency investigation of a report of medical neglect to infant care review committees. (See Preface, NOTES A and B.) The agency's *Guidelines for Medical Neglect of Disabled Infants* state that all medical neglect cases will be handled by a three-part system of infant care review committees (ICRC). The guidelines describe a system in which treatment decisions are made by the hospital's ICRC or, if such a committee does not exist at the hospital, a regional ICRC. A statewide committee is also to be available for guidance, advice, and precedent case decisions on "multiple congenital malformation syndromes incompatible with life." If a complaint is filed with the CPS agency, the guidelines state: "Cases reported directly to CPS will be handled in the same manner with initial (local in-hospital), secondary (regional ICRC), and if necessary, tertiary (statewide) reviews."[80]

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[76] *Id.*, §3.4.17.6(2).

[77] *Id.*, §3.4.17.5(4).

[78] Telephone interview with Gerald Gouge, Chief, Child Protective Services Unit, Division of Family and Children Services (July 20, 1988).

[79] *Id.*

The CPS guidelines rationalize this abdication of responsibility and perhaps attempt to dispel fear of liability for this system by stating:

> As the ICRCs work in close association with CPS and committee members they would be afforded the same legal immunities or safeguards as CPS workers since in effect they would be acting as consultants, advisors to CPS and the State of Georgia. These safeguards are supported by the Attorney General's Office.[81]

The Georgia procedure lacks methods to secure review of medical records or an independent medical examination. Instead, the State CPS agency defers entirely to the judgments of infant care review committees. Georgia is fundamentally out of compliance with the CAA and their implementing regulations.

HAWAII

In Hawaii, the Child Protective Services Unit within the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

Program assistants developed the investigative procedures for implementation of the Federal regulations. The agency reported that neither medical nor disability rights groups were consulted.[82]

The agency stated that no reports of medical discrimination have come to its attention since the regulation went into effect.[83]

Hawaii's procedures for an investigation of a medical neglect report were reviewed for compliance with the Federal regulation that implement the CAA. In contravention of Federal regulatory requirements, the procedures themselves fail to specify in writing the manner in which agency staff will obtain a court order for an independent medical examination of the infant, although the agency possesses authority to seek one.[84]

The most serious failure of compliance is that the CPS agency has abdicated its duty to investigate reports of medical neglect to decide whether illegal denial of treatment is taking place. The procedures direct the CPS worker to log a medical neglect report "as *a non-CPS case* if the treating physician does not recommend treatment and a second medical opinion (including another physician, the hospital's review committee, the Hawaii Medical Association's review committee, CPS Team physician) concurs with this recommendation."[85] Although a CPS team physician is mentioned, in short, a physician who wishes to deny treatment in violation of the standard of care established by the CAA need merely find one other physician or a review committee to agree in order to prevent any intervention by the CPS agency on behalf of the child's right to receive treatment. This clearly runs counter to the requirement of the CAA that the CPS agency serve as an independent investigating authority to ensure that the Federal standard of care is provided to the disabled infant.

Commenting on a draft of relevant portions of the Commission's report, the administrator of Services Program Development of the Hawaii Department of Human Services stated:

> Section 1100.9.2 states in effect that further investigation may not be required if inquiry by child protective services staff, upon receiving a report of alleged medical neglect, finds that a second opinion concurs with the opinion of the treating physician. By requiring initial investigative action by child protective services following receipt of a report, this procedural guideline does not completely abdicate the investigative responsibility to an infant care review committee but serves to assist the investigator in the process of disposition.

Far from refuting, this confirms that the Hawaii CPS abdicates its responsibility to physicians selected by the physician or hospital against whom a complaint has been lodged the determination of whether legally mandated treatment requirements are being met. (See Preface, NOTE A.) Hawaii should ensure that medical consultants not affiliated with the hospital or physician charged with neglect are made available to assist the CPS worker in the investigation of a report of withholding of medically indicated treatment of a handicapped infant.

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[80] Georgia Department of Human Resources, Child Protective Services Manual, sec. 2103.14, app. H, *Guidelines for Medical Neglect of Disabled Infants*, at 4.

[81] *Id.* at 2.

[82] Telephone interview with Stanley Inkyo, Program Administrator, Child Protective Services, by *Issues in Law and Medicine* (July 6, 1987).

[83] Telephone interview with Stanley Inkyo, Program Administrator, Child Protective Services, by Commission staff (July 28, 1988).

[84] Hawaii Rev. Stat. §587-21.

[85] Child Protective Services Policy Manual sec. 1100.9.2 (June 1987). Emphasis added.

Hawaii is fundamentally out of compliance with the CAA and its implementing regulation.

IDAHO

The Idaho Department of Health and Welfare is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

Agency personnel reported that they have had no reports of medical neglect of infants with disabilities since the regulation went into effect.[86]

The agency reported in a January 3, 1988, letter to the Commission that: "In our formulation stage of preparing draft policy and procedures on this topic a committee was convened to draft proposed materials. This committee included the Chief of the Bureau of Developmental Disabilities of the Department of Health and Welfare. He received input from appropriate groups to include the Downs Syndrome Parents Groups, Coalition of Advocates for the Disabled, and other parents support groups for children with various disabilities."

The agency procedures were reviewed for compliance with the Federal regulation that implements the CAA.

All definitions of terms mirror the Federal standards. As required by Federal regulations, CPS social workers are instructed to "obtain a copy of the infant's medical treatment record from the health care facility or hospital as a function of the investigation process. . . ."[87] In addition, the procedures meet the Federal requirement to provide for obtaining a court order for an independent medical examination of the infant when cooperation from the medical provider is not forthcoming.[88]

The procedures indicate that the agency alone is responsible for determining whether appropriate treatment is provided. The determination of whether illegal withholding of medical treatment is taking place is vested in the medical chief, Bureau of Child Health:

> The initial determination that withholding of medically indicated treatment as defined in Manual Section 3-2304.03 is occurring or is being prescribed by the infant's physician, will be made by the Medical Chief, Bureau of Child Health or his designee, with or without independent medical examination.[89]

On their face, Idaho procedures appear to comply with the requirements of the CAA and its implementing regulation.

ILLINOIS

The Illinois Department of Children and Family Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

Regarding reports of incidents of medical neglect of infants with disabilities, Illinois stated:

> Fortunately, the number of reports alleging the withholding of medically indicated treatment from disabled infants has remained small. This low level may be the result of cooperative efforts between the Department of Children and Family Services, the Illinois State Medical Society and other service providers which have focused their efforts on expanding the availability of support resources to troubled families.
>
> During FY 86 (July 1, 1985 through June 30, 1986) a total of ten *medical neglect of disabled infants* allegations were made. After investigations, three were indicated.
>
> So far, during FY 87 (July 1, 1986 to date) one allegation was made. After a thorough investigation, this case was indicated.[90]

In response to followup inquiry by Commission staff, the department stated that during FY 88 (July 1, 1987, through June 30, 1988) it had received three reports. After investigation, two were found to be indicated (i.e., a violation was found).[91]

The agency reported that it consulted the Illinois State Medical Society when it developed procedures for the investigation of a report of withholding medical treatment from a disabled infant. There was no indication that disability rights groups were consulted.[92]

The procedures were reviewed for compliance with the Federal regulation that implements the CAA. The definitions of terms correctly reflect the Federal standards. In accord with the Federal regulations, the procedures specify the manner in which the Department will obtain "administrative subpoenas or court orders to obtain access to hospital staff or records. . . ." and the manner in which it will obtain court orders for independent medical examinations.[93]

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[86] Telephone interview with Ed Van Dusen, Social Services Coordinator, Department of Health and Welfare (July 20, 1988).

[87] Social Services Manual, sec. 3-2305.06(c).

[88] *Id.*, sec. 3-2305.13.

[89] *Id.*, sec. 3-2305.08.

[90] Letter from Bobby J. Hall, Program Specialist, Department of Children and Family Services, to *Issues and Law and Medicine* (Mar. 30, 1987) (emphasis in the original).

[91] Telephone interview with Foster Centola, Program Specialist, Department of Children and Family Services (July 20, 1988).

[92] Telephone interview with Bobby J. Hall, Program Specialist, Department of Children and Family Services (June 1987).

The department has engaged a "perinatal coordinator" to advise the social worker investigating a report of whether treatment is necessary, to arrange independent medical evaluations, and if necessary, to advise whether the child should be taken into protective custody. This person is a medical specialist who practices at a special care nursery for infants. The procedures direct: "All reports of medical neglect of disabled newborns and infants under one year of age must be reviewed by the Department's Perinatal Coordinator."[94] The department procedures delineate the particular roles of the perinatal coordinator and the CPS worker:

> The Perinatal Coordinator shall provide a professional judgment whether there is evidence of medical neglect for each report of medical neglect involving a disabled infant under one year of age. However, the investigative worker is responsible for making the recommendation of indicated or unfounded based upon the Perinatal Coordinator's judgment and other facts of the report.[95]

The procedures acknowledge the existence of hospital infant care review committees but correctly recognize that their judgments on treatment may not be correct and are not binding upon the CPS: "Whenever a hospital has an Infant Care Review Committee, Department investigative staff or the Perinatal Coordinator will consult with the Committee and will document, in writing, any disagreements with the Committee's recommendations and the reasons for them."[96]

On their face, the Illinois procedures appear to comply with the CAA and their implementing regulation.

IOWA

In Iowa, the Child Protective Services Program within the Bureau of Adult, Children and Family Services of the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In developing procedures for the investigation of a report of medical neglect of an infant with a disability, the agency reported that it had consulted the Iowa Medical Association, the Iowa Hospital Association, and the Iowa Academy of Pediatrics. There is no indication that disability rights groups were consulted.[97]

The agency stated that no reports of medical neglect of disabled infants had been received since the regulation went into effect.[98]

The Iowa procedures are set forth in a cover memorandum from the CPS to the chief executive officers of Iowa health care facilities.[99] These procedures were reviewed for compliance with the Federal regulations that implement the CAA.

The State code includes a definition of "withholding of medically indicated treatment," establishing a standard of care that conforms to Federal law although this definition is absent from the agency's procedures manual. The procedures manual properly states the definition of the protected class of infants.

The Federal requirement that an agency have a specified method to gain access to an infant's medical records is met where the procedures provide that: "Court action may be necessary to secure access to medical records or other pertinent information when access is necessary to assure an appropriate investigation."[100] The procedures do not expressly state the manner in which the agency will obtain a court order for an independent medical examination, as required by 45 C.F.R. §1340.15(4)(ii) (see Preface, NOTE D).

It appears that the agency has agreements with four independent medical examiners, chosen by the Iowa chapter of the Academy of Pediatrics, to assist CPS investigators with reports of medical neglect.[101]

The agency procedures delineate the particular roles of the "medical consultant" and the CPS worker: "The medical consultant will assist the worker in evaluating all medical information. The amount of assistance rendered by the medical consultant shall be jointly determined by the worker and the medical consultant, based upon the needs of the case."[102]

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[93] Department of Children and Family Services, Rules and Procedures, sec. 302.130 (i), 160 (g).

[94] *Id.*, sec. 302.130 (i)(2)(B).

[95] *Id.*

[96] *Id.*, sec. 302.190 app. A.

[97] Telephone interview with Tim Barber-Lindstrum, Program Manager, Child Protective Services, by *Issues in Law and Medicine* (June 12, 1987).

[98] Telephone interview with John Holcamp, Program Manager, Child Protective Services (Aug. 4, 1988).

[99] Memorandum from Timothy Barber-Lindstrum, Program Manager, Child Protective Services, to Chief Executive Officers, Iowa Health Care Facilities, Subject: Baby Doe Procedures (June 23, 1987).

[100] *Id.* at 4.

[101] Information obtained from Tim Barber-Lindstrum, Program Manager, Child Protective Services, by *Issues in Law and Medicine* (June 12, 1987).

On the face of its procedures, the agency appears ready to evaluate both parental refusals to consent to treatment and attending physician decisions to deny treatment to an infant. The memo does not reflect an abdication of responsibility to a hospital's infant care review committee on the question whether treatment (or nontreatment) is legally correct.

With the exception of the failure to describe the manner in which court orders will be obtained for independent medical examinations, the Iowa procedures on their face appear to comply with the requirements of the CAA and their implementing regulation.

KANSAS

In Kansas, Youth Services within the Department of Social and Rehabilitation Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In developing its approach to implementation of investigation procedures, the agency stated, "The Department did not consult disability rights groups. We did consult medical experts, hospitals, and the Kansas Regional Perinatal Medical Committee."[103]

The agency said that there had been no reports of withholding of medically indicated treatment from infants with disabilities since the CAA went into effect.[104]

The Kansas agency's procedures were reviewed for compliance with Federal regulations. Definitions for "withholding of medically indicated treatment," establishing the standard of care, and "infant," establishing the class protected, are included and accurately restate the Federal standard. The enforcement mechanisms that are required by the Federal regulation to be specified in the agency's procedures, such as the manner in which the CPS will obtain medical records and a court order for independent medical evaluation, are also set forth. The procedures provide that an independent medical consultant is available from either one of the State's perinatal center hospitals. It specifies that a medical consultant from the other hospital shall be used in the event a case is reported in one of these centers.

On their face, the Kansas procedures appear to comply with the CAA and their implementing regulation.

KENTUCKY

In Kentucky, the Child Protective Services unit within the Department for Social Services of the Cabinet for Human Resources is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it consulted the Easter Seals Hospital for assistance in developing a procedure for investigation.[105] It gave no indication that disability rights groups had been consulted.

The agency said that there had been only one case reported since the CAA went into effect, and that was not considered to involve denial of treatment based on disability, since the parents wished to withhold treatment because of religious principles. A court order for treatment was readily obtained. A CPS specialist stated that there had been "only one reported Baby Doe case in the three years I've been here. Of course, we hear through the grapevine from medical personnel that cases go unreported."[106]

Despite this, the agency appears to have actively responded to the requirements of the CAA, and the agency procedures indicate that the agency has established a toll-free hotline so that "medical personnel or other interested persons can notify the Department of suspected or known instances of the withholding of medically indicated treatment of disabled infants with life-threatening conditions in hospitals or health care facilities."[107]

The agency's procedures were reviewed for compliance with Federal regulation. Definitions of "withholding of medically indicated treatment," establishing the standard of care, and "infant," establishing the class protected, are included and accurately restate those in the Federal regulation. The enforcement mechanisms required by the Federal regulation to be specified in the agency's procedures, such as the manner in which CPS will obtain medical records and court orders for independent medical evaluations, are included. The procedures provide for an independent medical consultant to be available for an investigation of a medical neglect report. The procedures state: "Upon receipt of a report of suspected medical neglect of a handicapped infant in a hospital (from the hotline or local staff), the designated Central Office staff indicated above will immediately notify one of the Department's medical consultants. The medical consultant will immediately investigate the report."[108] The agency reported that two specialists from two perinatal centers in the State, one in the eastern part of the State, the other in the west, are under contract with the State to respond to the reports. To avoid professional conflicts, if a report is from the west, the specialist from the east responds and vice versa for a report from the east.[109]

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[102] Memorandum from Timothy Barber-Lindstrum, Program Manager, Child Protective Services to Chief Executive Officers, Iowa Health Care Facilities, Subject: Baby Doe Procedures, at 4. (June 23, 1987).

[103] Telephone interview with Roberta Sue McKenna, Attorney, Youth Services, by *Issues in Law and Medicine* (Apr. 10, 1987).

[104] Telephone interview with Roberta Sue McKenna, Attorney, Youth Services (Aug. 3, 1988).

[105] Telephone interview with Betsy Farley, Child Protective Services, by *Issues in Law and Medicine* (June 22, 1987).

[106] Telephone interview with Michele Gore, Child Protective Services Specialist, Child Protective Services (July 21, 1988).

[107] Family and Children's Services Manual, ch. IV, A. 11

On their face, the Kentucky procedures appear to comply with the CAA and their implementing regulation.

LOUISIANA

In Louisiana, the Division of Children, Youth and Family Services of the Office of Human Development in the Department of Health and Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In response to a Commission inquiry, the agency stated that "the hospitals had not reported any cases."[110]

The State agency's policies and procedures were reviewed for compliance with the Federal regulation that implements the CAA. Louisiana's procedures are contained in *A Statewide Program for the Implementation of Procedures for the Reporting and Investigation of Suspected Instances of Medical Neglect of Disabled Infants.* This is a comprehensive manual for the investigation of a Baby Doe report and appears to implement much of HHS's supplementary information in the final regulation. The manual offers step-by-step investigation directions and has appendices with pertinent questions for the hospital liaison, the parents, and the hospital's infant care review committee.

Definitions presented in the manual fully conform to those contained in the Federal regulation. The enforcement mechanisms required by the Federal regulation to be specified in the agency's procedures are included in the manual, including the manner in which the CPS agency will obtain medical records or court orders for independent medical evaluations. The manual provides for an independent medical consultant to provide assistance to the CPS investigator. The agency reported that the State has contracted with 14 physicians across the State to assist in these cases.[111]

On their face, Louisiana's procedures appear to comply with the CAA and their implementing regulation.

MAINE

In Maine, Child Protective Services within the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it has received no reports of medical neglect of infants with disabilities since the CAA went into effect.[112]

In developing procedures for implementation of the CAA, the agency reported that it had consulted with individuals from hospitals and medical associations; disability rights groups were not consulted.[113]

The State agency's procedures were reviewed for compliance with the Federal regulation implementing the CAA. Enforcement mechanisms required by the Federal regulation to be specified in CPS agency procedures, such as the manner in which a CPS agency will obtain medical records and court orders for independent medical evaluations, are included. The intake procedures include a definition of "withholding of medically indicated treatment," establishing the standard of care, that mirrors the Federal definition. However, there is no definition for the term "infant," meaning that the protected class is not described. This is a significant omission.[114] (See Preface, NOTE E.) The procedures also direct that, if an allegation of withholding of medically indicated treatment meets the Federal standard, the CPS worker should alert the central office program manager. The procedures then require:

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[108] *Id.*

[109] Telephone interview with Betsy Farly, Child Protective Services, by *Issues in Law and Medicine* (June 22, 1987).

[110] Telephone interview with Terry Gibson, Bureau Director, Division of Family, Youth and Family Services (July 21, 1988).

[111] Telephone interview with Sue Steib, CPS Specialist, Division of Children, Youth and Family Services, by *Issues in Law and Medicine* (June 1, 1987).

[112] Telephone interview with Phyllis Miriam, Child Protection Program Consultant, Department of Human Services (July 27, 1988).

[113] Telephone interview with Barbara Churchill, Department of Human Services, by *Issues in Law and Medicine* (June 15, 1987).

> (2) The Program Manager to seek medical consultation and contact the designated hospital liasion personnel.
>
> (3) If the allegations are confirmed, and with consultation by the Central Office Program Manager and the Assistant Attorney General, the regional office staff will seek a Medical Treatment Order.[115]

This procedure appears to meet the regulatory requirement for independent CPS investigation of a report of medical neglect of an infant with a disability. The agency reported that an employee of the Maine Bureau of Health is the designated medical reviewer.[116] However, a "Fact Sheet" interpreting the CAA that was distributed by the central agency office to all CPS regional program managers in April 1985 misstates the legal responsibilities of the CPS. The fact sheet, developed by an organization known as Action for Child Protection, gives general background information on legal requirements of the CAA. In a question and answer format designed to instruct a CPS audience, the following misstatements of law are given:

> 4. QUESTION: What is required of CPS in receiving suspected reports of medical neglect of handicapped infants?
>
> ANSWER: The CPS response would be similar as in all other reports of medical neglect. Upon receiving a report, CPS must first verify, through consultation with the treating physician, review team, or other hospital designee that adequate nutrition, hydration, and medication is being given to the infant, whether special medical attention is needed to correct a life-threatening condition, and whether legal intervention is required.[117]

This response misstates the law by giving the hospital that is being investigated because its staff is accused of medical neglect the task of informing the investigator "whether legal intervention is required." The pamphlet goes on to say:

> 7. QUESTION: Does CPS have to get involved if the treating physician and the child's parents are in agreement to withhold treatment from a handicapped infant?
>
> ANSWER: New procedures should provide for CPS to utilize medical consultants such as a hospital Infant Care Review Committee to determine if treatment is "medically indicated." Again, determination if treatment is "medically indicated" is made by a reasonably prudent physician as defined above. If the treating physician, and the Infant Care Review Committee or hospital designee agree that treatment is not "medically indicated" CPS does not need to further investigate.[118]

This, of course, is contrary to the defined roles of the CPS and the infant care review committee set forth in the Federal regulation. The determination whether treatment is medically indicated is a CPS decision, not to be abdicated to a review committee at the hospital being investigated. (See Preface, NOTE A.)[119]

Apart from their failure to define the protected class, on their face the Maine procedures appear to comply with the CAA and their implementing regulation. However, the distribution of the Action for Child Protection Fact Sheet raises significant questions about whether Maine CPS workers have erroneously been led to believe that they should uncritically defer to the conclusions of hospital infant care review committees.

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[114] Commenting on a draft of relevant portions of the Commission report, the agency stated:

> "infant" is not defined in statute or policy in Maine but the definition in the policy [enclosed] was the federal definition for what cases require investigation by the Department and if substantiated specify that court protection be sought for that infant.

Letter from Sandra S. Hodge, Program Manager, Child Protective Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 12, 1988). Although the referenced policy includes a definition of withholding of medically indicated treatment that *uses* the term "infant," it nowhere *defines* "infant."

[115] Department of Human Services Policy Manual, C. Intake Screening, 8.(a).

[116] Telephone interview with Sandra Hodge, Child Protection Services Program Manager, Department of Human Services, by *Issues in Law and Medicine* (June 15, 1987).

[117] Action for Child Protection *Fact Sheet*, NEW REQUIREMENTS FOR CPS AGENCIES, Regarding Cases Involving the Withholding of Treatment From Disabled Infants with Life-Threatening Conditions, question 4.

[118] *Id.*, question 7.

[119] In a letter dated Oct. 12, 1988, the agency responded to a preliminary draft of relevant portions of the Commission report. The Child Protective Services program manager, without making reference to the Fact Sheet, submitted the intake policy, also quoted above, to demonstrate that the agency makes the decision on the question of medical neglect. She wrote that:

> The material related to medical treatment clearly gives the decision making about whether a case meets the "Baby Doe" criteria to the Department not a hospital. The medical consultant is an employee of the Department. This section also directs that specific court action be taken by Department staff to protect the infant.

Letter from Sandra S. Hodge, Program Manager, Child Protective Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 12, 1988).

MARYLAND

In Maryland, the Child Protective Services Unit of the Social Services Administration within the Department of Human Resources is the State agency responsible for compliance with and enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it had received only one report of withholding medically indicated treatment since the regulation went into effect. This report, occurring in 1986, concerned an infant with anencephaly who was given proper care according to the investigation. The child died a week after his birth.[120]

The agency's investigation procedures for a medical neglect report were reviewed for compliance with the Federal regulations that implement the CAA. The "procedures were developed in consultation with the Maryland Hospital Association, the Fetus and Newborn Committee of the Maryland Academy of Pediatrics, and the Medical-Chirurgical Faculty of Maryland."[121] No disability rights groups were listed as being consulted.

Enforcement mechanisms required by the Federal regulation to be specified in CPS agency procedures, such as the manner in which a CPS agency will obtain medical records and a court order for independent medical evaluation, are set forth. In both the "preliminary" and "further investigation" procedure provisions, social workers are instructed that "[i]t may be necessary to petition the court in order to gain access to the child's medical records or to conduct or to obtain an on-site investigation or to obtain an independent medical examination."[122] CPS workers are further instructed to "[c]ontact the agency attorney so that compliance with the applicable laws may be determined."[123] These provisions appear to satisfy the Federal requirement that the State agency specify in its procedures the manner in which it will obtain access to medical records and/or other information and "a court order for an independent medical examination of the infant."[124]

The procedures establish a method for an independent medical examination of a child:

> Upon conclusion of the preliminary inquiry, the worker will consult with a medical expert specializing in the type of medical problem or disabling condition identified in the health care provider's preliminary report. The expert will assist the local department in understanding the medical reports and technical issues involved in determining whether medically indicated treatment is being withheld.[125]

The procedures provide that when further inquiry is needed:

> If it is not possible to determine from the preliminary inquiry and technical review whether medical neglect is "confirmed" or "ruled out" in the reported instance, the worker shall initiate further investigation, with the assistance of medical experts, into the circumstances of the case, in order to come to a determination of what further action, if any, is needed.[126]

The procedures include an accurate definition for "withholding of medically indicated treatment." However, there is no definition of the term "infant." In a letter dated September 28, 1988, commenting on a preliminary draft of relevant portions of this report, the program manager acknowledged the omission. However, he stated that under Maryland law protective services are provided "to any individual under the age of 18 years." With the important exception of their failure to define "infant," the Maryland procedures appear on their face to comply with the requirements of the amendments and their implementing regulation.[127]

However, as Preface NOTE E explains in detail, the standard of care the Child Abuse Amendments require for "disabled infants with life threatening conditions" is far more precise and detailed than the general language applicable to all minors. The failure to define "infant," so as to describe accurately the class of children protected, is a significant failing.

The agency's procedures appear on their face to be an approach to enforcement that is objective and adequate. They would be improved if the term

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[120] Telephone interview with Gisele Meek, Policy Specialist, Social Services Administration (Aug. 12, 1988).

[121] Memorandum from Frank Farrow, Executive Director, Maryland Department of Human Resources, to Chief Executive Officers, all Maryland Acute-Care Hospitals 2 (Oct. 4, 1985) (available in files of U.S. Commission on Civil Right).

[122] Social Services Administration Procedures Manual, Special Procedures, Policy .03, Procedure .01, para. 5, at 175.

[123] *Id.*

[124] 45 C.F.R. §1340.15(c)(4)(ii) (1987).

[125] *Id.*, Procedure .02 at 176.

[126] *Id.*, Procedure .05 at 176.

[127] Letter from Laura Skaff, D.P.A. to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Sept. 28, 1988).

"infant" were added to the procedure to lend clarity to enforcement.

MASSACHUSETTS

The Massachusetts Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it had received no reports of medical neglect of handicapped infants with life-threatening conditions since the regulation went into effect.[128]

In developing procedures for implementation of the CAA, the agency reported that it consulted with the New England Medical Center, the Federation for Children with Special Needs, the Developmental Disabilities Council, and a panel of 20 to 30 persons that included an ethicist from Boston City Hospital, attorneys, public health officials, neonatologists, and pediatricians.[129]

Agency procedures were reviewed for compliance with the Federal regulation implementing the CAA. All definitions of terms mirror the Federal standards. The procedures state that "[i]f necessary, a DSS attorney initiates appropriate court action to gain access to the hospital, medical information or medical examination of the reported infant."[130] These provisions would appear to satisfy, if in a somewhat cursory fashion, the Federal regulatory requirement of the CAA regulation that the State agency specify in its procedures the manner in which it will obtain access to medical records and court orders for independent medical examinations.

If there is a weakness in this policy, it is the fact that notwithstanding the instruction to the DSS attorney to "gain access. . .to an independent medical examination," there is little in the procedure that indicates that there is an independent third party medical examiner to assist the CPS. The procedures appear to instruct the CPS worker to rely on the medical information received from the hospital against which the complaint was lodged:

> After obtaining the signed consent of the infant's parents, the investigator determines from a review of the infant's medical record and an interview with the hospital representative the nature of the child's medical record and an interview with the hospital representative the nature of the child's medical condition(s); the proposed treatment; how the infant's course of treatment was selected; if alternative treatment options were considered; if physicians other than the primary physician participated in the formulation of the treatment plan and/or second opinions from other specialists were obtained; if there was consensus among the treatment providers (nurses, physicians, etc.) with regard to the appropriateness of the treatment; and if the treatment decisions were reviewed by a hospital Infant Care Review Committee or comparable review body.[131]

"Medical consultation" is not obtained until the investigation has been completed,[132] and no reference is made to an outside medical reviewer. The CPS worker appears to be alone in determining whether the medical establishment is providing appropriate treatment. The effectiveness of any investigation to discover if treatment is medically correct would be substantially improved were the agency to specify in its procedures the use of an independent third-party medical consultant, selected with the benefit of advice from disability groups, at an early enough stage to assist the CPS worker in investigating all nonfrivolous cases.

The procedures developed by this agency are in compliance with the Federal regulatory standards, although use of independent third-party medical personnel to assist the CPS in the determination of medically indicated treatment would substantially improve the ability of the CPS to make a truly independent determination on whether treatment being provided to the subject of a report is in fact in compliance with the standards of the CAA.

MICHIGAN

In Michigan, the Office of Children and Youth Services within the Department of Social Services is the State agency responsible for compliance with the Child Abuse Amendments of 1984 (CAA).

The agency stated in 1987 that:

> To date, Michigan has had only one report when medically indicated treatment was withheld from a disabled infant with a life-threatening condition. In this report, the parents, at first, did not consent to the recommended medical treatment. Prior to initiating court action, however, they consented for their child to be treated.[133]

Somewhat surprisingly, the agency responded to a followup inquiry that "the information system that we have does not factor out these types of cases. These cases are only classified as medical neglect."[134]

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[128] Telephone interview with Jane Waldfogel, Case Practice Specialist, Office of Professional Services, Department of Social Services, by Commission staff (July 22, 1988).

[129] Telephone interview with Judith Riley, Department of Social Services, by *Issues in Law and Medicine* (July 13, 1987).

[130] DSS Policy No. 86-010 at 4, para. 7.

[131] *Id.* at 3, para. 4.

[132] *Id.*, para. 5.

[133] Letter from Laura Daniel, Program Consultant, Department of Social Services, to *Issues in Law and Medicine* (Apr. 22, 1987).

In developing procedures for the implementation of the CAA, the agency reported that "[m]edical organizations and disability rights groups were involved in developing this policy."[135]

Agency procedures were reviewed for compliance with the Federal regulation that implement the CAA. Definitions of terms stated in the procedures mirror the Federal standards, and the procedures contain instructions for the CPS worker to petition a court for orders for review of medical records and independent medical evaluations, in accord with Federal requirements.

However, investigations are to be pursued only when a report alleges a parental refusal to consent to treatment for their child. When a parent or anonymous source reports to the agency that a hospital is withholding medically indicated treatment from an infant with a disability, the procedures expressly prohibit CPS involvement. The procedures state:

> CPS is responsible for responding to reports that *parents* are neglecting their child's health and welfare by withholding medically indicated treatment. . . .*Reports from parents or others that the hospital or health care provider is neglecting. . .provide proper or suitable care for the infant is outside the scope and responsibility of CPS, and are not appropriate referrals for CPS investigation.* Existing procedures including medical review committees within the health care facility are to be used for addressing such concerns.[136]

The Federal regulations clearly require that upon receiving a report the State's CPS system must make the determination whether treatment is medically indicated under the CAA. This self-imposed limitation on CPS investigations is inconsistent with the respective roles and responsibilities of the CPS and the infant care review committee, as set forth in the Federal regulations. (See Preface, NOTE A.) These procedures explicitly abdicate to the hospital the agency's responsibilities under Federal law to investigate and enforce the CAA.

The foregoing language allows the hospital that has had a complaint lodged against it to review the case, or to serve as the equivalent of an independent medical examiner. Because of the obvious conflicts of interest between the ICRC member's duty to the hospital, the child, and the parents, this runs counter to the requirements of the CAA that the CPS agency serve as the independent investigating authority to ensure that the Federal standard of care is provided to the infant with a disability.

Commenting on a draft of relevant portions of the Commission's report, the agency argued that the parents are legal guardians of the child and are thus the decisionmakers responsible for the child's health and welfare; if the parents act responsibly, there is no basis for involvement of the CPS agency.

The agency stated:

> Based on the preceding discussion that parents are the decision makers concerning the care and treatment for their disabled infant, CPS involvement is appropriate when *parents* are alleged to be neglecting their infant's care. An entity which is not the decision maker or responsible for the child's care is not appropriate for CPS involvement.[137]

Whatever may be the case with regard to other forms of child abuse and neglect, however, Federal law requires that State agencies receiving Federal funds do what is necessary to prevent illegal denial of treatment to children with disabilities. The statute provides that to qualify for Federal funding, a CPS agency must possess:

> authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.[138]

This language encompasses circumstances in which medical providers, as well as parents, are withholding legally mandated treatment.

The agency's response goes on to state that "where it is alleged there is collusion between the parents and the medical care provider to neglect a child's health or welfare, CPS involvement is appropriate." Although the agency may assert that it investigates reports of this nature, there is no indication of this category, although it is the typical denial of treatment situation the CAA was enacted to address.

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[134] Telephone interview with Henry Hofstra, Program Consultant, Department of Social Services (July 25, 1988).

[135] Letter from Laura Daniel, Program Consultant, Department of Social Services, to *Issues in Law and Medicine* (Apr. 22, 1987).

[136] Michigan Department of Social Services, Children and Youth Services Manual (1986) (emphasis added).

[137] Letter from C. Patrick Babcock, Director, Michigan Department of Social Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 10, 1988) (emphasis in original).

[138] 42 U.S.C.A. §5103(2)(k)(iii) (West Supp. 1988).

Michigan should obtain an independent medical consultant, not affiliated with the hospital, to assist the CPS in the investigation of a report of withholding of medically indicated treatment to a handicapped infant (see Preface, NOTES A and B).

Michigan presents a case of a State CPS agency that has wrongfully delegated to the hospital ICRCs the legal question of whether there is a withholding of medically indicated treatment. In so doing, the agency has distorted the CAA's intent to create a strong enforcement mechanism for the treatment of disabled children.

Michigan operates on the premise, stated in its procedures, that "[m]ost reports of medical neglect involving the withholding of medically indicated treatment from infants with life-threatening conditions by parents will originate from a health care provider or hospital. It is logically in the best position, with its medical expertise to know what is medically indicated and necessary treatment."[139]

Accordingly, its investigative procedures provide for heavy reliance on the hospital's position on whether treatment should be provided.[140] Only when "there remains some doubt or uncertainty regarding the hospital's recommendation, the parent's refusal to authorize medically indicated treatment, or there is a need for additional documentation to arrive at a conclusion" do the procedures provide for possible consultation with a "medical consultant."[141]

Throughout the crucial decisionmaking in most investigations, therefore, the medically untrained CPS worker appears to be alone in determining whether the health care facility is providing appropriate treatment, relying solely on medical information and analysis by personnel at that facility.

This approach fundamentally misconceives the nature of the problem the CAA were enacted to confront. As chapter 2 of this report suggests, in many cases in which parents nominally agree to deny treatment, they have been heavily influenced by the information and advice of the health care providers. Michigan's reliance on those same providers as the primary source for assessment of whether legally mandated medically indicated treatment is being withheld is not likely to result in fulfilling the statutory mandate to ensure that such treatment is provided.

The effectiveness of Michigan's investigations would be significantly improved were the agency to specify procedures for the use of an independent third-party medical consultant, selected with the benefit of advice from disability rights groups, to assist the CPS worker in all nonfrivolous cases.

Although Michigan's definitions of the standard of care and class protected, as well as its provisions for access to medical records and for a court order to secure an independent medical examination, appear on their face to be in technical compliance with the CAA and their implementing regulation, Michigan's failure to provide for independent investigations and its unwarranted apparent deference to health care providers raise serious questions concerning its substantial compliance.

MINNESOTA

In Minnesota, the Child Protection Program in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that it had not "had any reports of withholding of medically indicated treatment from disabled infants since the amendments to the national child abuse act came into effect."[142] In response to a followup inquiry by the Commission, the agency confirmed that it had not received any reports.[143]

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[139] Michigan Department of Social Services, Children and Youth Services Manual 47 (1986). If a report comes "from someone other than a health care provider or hospital," it is to be investigated only if there is "reasonable cause to believe" the report:

> Reasonable cause to believe is defined as: what reasonable people, in similar circumstances, would conclude from such things as the nature of the condition of the child, health care professional statements, and information that the parents have refused to consent to recommended treatment.

Id. at 53.

[140] *Id.* at 47-49; *see also id.* at 53 (even when report is received from someone other than a health care provider, if an investigation is warranted, it is to be conducted "under the steps indicated. . .for responding to a report received from a health care provider or hospital").

[141] *Id.* at 50. Even then, the consultant is part on a par with internal hospital sources; under the described circumstances, "there should be further consultation with ICRC, other review committee or medical consultant, if available."

[142] Letter from John Langworthy, Child Protection Specialist, Department of Human Services, to *Issues in Law and Medicine* (Apr. 3, 1987).

[143] Telephone interview with Sara McNeely, Child Protection Program Advisor, Department of Human Services (Aug. 3, 1988).

The agency reported that it developed its procedures by contracting with the Minnesota Hospital Association to formulate them. There is no indication that disability groups were consulted.[144] The result was a publication entitled *Guidelines for Responding to a Report of Suspected Medical Neglect of a Hospitalized Disabled Infant with a Life-Threatening Condition.* The publication states that the guidelines were developed for the Minnesota Department of Human Services under a grant from HHS and were prepared by the Technical Advisory Committee to the Minnesota Baby Doe Implementation Project, Minnesota Hospital Education, Research Trust Fund, and the Minnesota Hospital Association.

The guidelines were reviewed for compliance with the Federal regulation implementing the CAA. The manual offers step-by-step investigation directions and has appendices that instruct the CPS on developing information on the case and how to come to a conclusion whether treatment is "medically indicated."

The enforcement mechanisms required by the Federal regulation to be specified in the agency's procedures are present in the manual. These include the manner in which CPS will obtain medical records and court orders for independent medical examinations. The manual provides for an independent medical consultant to be available to provide assistance to the CPS worker at each phase of the investigation. The standard of care defined in the manual conforms to the Federal regulation.

However, its definition of "infant" is limited to those under 1 year of age, an underinclusive definition of the protected class.[145] In a letter dated September 30, 1988, the acting supervisor of Child Protective Services addressed this shortcoming in responding to a draft of relevant portions of the Commission report. The acting supervisor argued that other provisions protect older children against medical neglect. This position fails to recognize that the general standards concerning medical neglect for all children are dramatically less detailed and precise than those the CAA makes applicable to "disabled infants with life-threatening conditions (see Preface, NOTE E).

Apart from their underinclusive definition of the protected class, which is a significant failing, the Minnesota procedures appear to comply with the CAA and their implementing regulation.

MISSISSIPPI

In Mississippi, the Protection Department within the Department of Public Welfare is the agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it had not received any reports of possible withholding of medically indicated treatment from infants with disabilities who had life-threatening conditions.[146]

In developing procedures for the implementation of the CAA, the agency reported it had consulted the University of Mississippi Hospital, Mississippi Medical Association, and the Mississippi Hospital Association. There is no indication that disability rights groups were consulted.[147]

Agency procedures were reviewed for compliance with the Federal regulation that implements the CAA. The procedures are limited to one page and lack provisions that are required by Federal law for agency compliance. The substance of the current policy can be described as nothing more than instructions on what persons to interview and where to send the report regarding disposition of the case. Although the 1985 manual adequately met the requirements of the CAA, the 1988 Child Protective Services manual does not.

The current procedures fail to define the required standard of care (see Preface, NOTE F) or to describe the class to be protected by it (see Preface, NOTE E). Contrary to Federal regulatory requirements, they do not specify in writing either the manner in which the agency will obtain access to medical records or the manner in which it will obtain court orders for independent medical examinations.

Furthermore, the procedures appear to instruct the CPS worker to rely on the medical information received from the hospital against which the complaint was lodged; they make no provision for an independent assessment by a medical consultant:

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[144] *Id.*

[145] Minnesota Rules, part 9560.0218, subpart 1 (1988); Minnesota Department of Human Services, Social Services Manual XVI-4120.5 (1987); Guidelines for Responding to a Report of Suspected Medical Neglect of a Hospitalized Disabled Infant with Life-Threatening Condition (1986).

[146] Letter from Melzana Fuller, Programs Manager, Child Protection Services Unit (Aug. 19, 1988).

[147] Letter from Melzana Fuller, Programs Manager, Child Protection Services Unit, to *Issues in Law and Medicine* (Apr. 6, 1987).

> b. Reports received in county are reported immediately, to the Area Social Work Supervisor who will investigate.
>
> c. Area Social Work Supervisor is to:
>
> 1) Notify immediately the designated contact health care facility and Child Protective Services Unit.
>
> 2) Interview at health care facility:
>
> a) Designated contact person
>
> b) Family
>
> c) Others involved with the infant[148]

Upon inquiry, the agency reported that it would not have a "child specialist." Instead, the agency indicated that it uses a social worker from the child protective staff and, if necessary, consults with physicians.[149]

Mississippi's procedures appear to be ad hoc and incomplete. In every significant respect, they fail to comply with the requirements of the CAA and its implementing regulation.

MISSOURI

Missouri Children's Services in the Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In 1987 the agency stated, "We have not received any reports of possible withholding of medically indicated treatment from disabled infants with life threatening conditions."[150] In response to a follow-up inquiry by the Commission, the agency stated that it was not aware of any such cases reported to it in the past year.[151]

In developing procedures to implement the CAA, the agency reported that it used material from the American Bar Association and discussed the procedures "with the Missouri Hospital Association and physicians associated with the Division of Medical Services—the State Medicaid agency."[152] The agency gave no indication that disability groups were consulted.

Agency procedures were reviewed for compliance with the Federal regulations that implement the CAA. The agency's procedures contained a definition for "withholding of medically indicated treatment" that fully conforms with the Federal standard.

A deficiency in the policy is that there is no definition for the term "infant," leaving the class protected by the standard of care unclear. In response to this criticism, the agency argued that because the State statute defines "child" in its medical neglect statute as one under 18 years of age, and it will investigate any report of medical neglect against a child, it, therefore, need not be more specific in its procedures.[153] This argument fails to recognize the necessity of applying the more detailed standards of the CAA to the class of "disabled infants." (See Preface, NOTE E.)

The procedures specify the manner in which the CPS agency will obtain medical records and court orders for independent medical evaluations as required by Federal regulation. The manual provides for an independent medical consultant to be available from "the Division of Medical Services or other independent doctors to determine if appropriate medical and nutritional services are being provided."[154]

Despite its statement that there will be an independent agency medical evaluation available, there is evidence that the agency assigns a substantial amount of its investigative and decisionmaking authority to a hospital's infant care review committee (ICRC). The policy states:

> In the event of the following circumstances the CSW (Child Services Worker) or other appropriate DFS personnel should inform the parent that a recommendation will be made to the Juvenile Court to secure a court order for an independent medical examination.
>
> When the parent(s) of the infant does not consent to review of the infant's treatment;

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[148] Child Protective Services Procedure For Service Activity, vol. IV, sec. B at 2014 (1988).

[149] Telephone interview with Melzana Fuller, Programs Manager, Child Protection Services Unit, by *Issues in Law and Medicine* (June 1, 1987).

[150] Letter from Melody Emmert, Deputy Director, Children's Services, to *Issues in Law and Medicine* (Apr. 8, 1987).

[151] Telephone interview with Fred Proebsting, Program Development Specialist, Children's Services (July 25, 1988).

[152] Letter from Melody Emmert, Deputy Director, Children's Services, to *Issues in Law and Medicine* (Apr. 8, 1987).

[153] Letter from Melody A. Emment, Deputy Director, Missouri Children's Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 7, 1988).

[154] Children's Section Special Child Abuse/Neglect Investigation Procedure: Baby Doe, No. A-7, para. 7.

> *When the attending physician and/or parents does not agree with the recommendation of the Review Committee;*
>
> When there is no Review Committee and the parent(s) does not consent to a consultation and/or individual medical examination.[155]

At least in some circumstances, the foregoing language allows the hospital that has had a complaint lodged against it to review the case, or to serve as the equivalent of an independent medical examiner.

In a letter commenting on a draft of relevant portions of the Commission report, the deputy director of Children's Services wrote, "Our policy clearly allows for our staff to request a court order in any situation where they believe an independent examination is required. Item I above refers to consent for any review, not only the Infant Care Review Committee."[156] Although, given this clarification, it appears that the agency retains independent authority to initiate a medical examination, it remains the case that, at least in some circumstances, Missouri appears to regard a committee of the hospital against whose staff the complaint has been lodged as a legitimate review board. (See Preface, NOTE B.)

Because of its failure to define adequately the class protected by the standard of care, and what appears, in at least some circumstances, to be its improper deference to hospital infant care review committees, Missouri is out of compliance with the CAA and their implementing regulation in significant respects.

MONTANA

In Montana, the Department of Family Services in the Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it had not received any reports of medical neglect of infants with disabilities since the regulation went into effect.[157]

In response to an inquiry about the participation of outside groups in the development of procedures to implement the CAA, the agency reported they were created by agency staff in a wholly internal process.[158]

Agency procedures are very brief and based on earlier regulation issued under section 504 of the Rehabilitation Act of 1973, rather than those implementing the CAA.

Although the terms are defined in the State's child abuse statutes, the federally required standard of care and definition of those protected by it are absent from the Montana procedures.

Agency policy shows that CPS staff have the ability to initiate independent medical examination of infants in cases of suspected medical neglect and provides for obtaining access to medical records consistent with Federal regulatory requirements.

In response to a Commission inquiry regarding medical technical assistance to the CPS worker, the agency reported that the State had a contract with the Montana chapter of the American Academy of Pediatrics, and that this organization would immediately contact a specialist in the area. The agency stated that the Academy-designated physician and the attending physician would conduct a "joint examination." When asked whether the CPS worker would have to rely heavily on the pediatrician in determining whether treatment was in fact medical neglect of a child with a disability, the agency responded that the decision was a medical decision and not a decision for the social worker.[159] The Federal regulations are clear, however, that it is the State's CPS system that must make the determination whether treatment is medically indicated under the CAA and whether circumstances exist to invoke the power of the State (see Preface, NOTE A). Involving the very physician who presumably is the subject of a report alleging illegal denial of treatment in a "joint examination" to determine whether the report is well founded creates an obvious conflict of interest, and gives little assurance that there will be a searching and arms-length investigation of the charges.

Montana's CPS has developed procedures that meet the requirements of current Federal regulations. However, the practice of deferring the legal question of medical neglect to a physician indicates a fundamental misunderstanding of the role of the CPS in enforcing the CAA.

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[155] *Id.*, para. 8 (emphasis added).

[156] Letter from Melody A. Emmert, Deputy Director, Missouri Children's Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 7, 1988).

[157] Telephone interview with Gary Walsh, Administrator of Policy and Planning and Evaluation, Department of Family Services (Aug. 3, 1988).

[158] Telephone interview with John Madsen, Department of Social and Rehabilitation Services, by *Issues in Law and Medicine* (June 1, 1987).

[159] Telephone interview with John Madsen, Department of Social and Rehabilitation Services, by *Issues in Law and Medicine* (June 1, 1987).

NEBRASKA

In Nebraska, the Human Services Division within the Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it had not received a report of medical neglect of an infant with a disability since the regulation went into effect.[160]

The procedures for implementation of the CAA appear to exist as ad hoc administrative memoranda from the director of the Department of Social Services. Two memoranda appear as evidence of the agency's policy on medical neglect of handicapped infants. They were reviewed for compliance with the Federal regulation implementing the CAA.

The first directive, dated October 8, 1985, instructs CPS workers to refer all reports of suspected medical neglect of disabled infants to the department's central office or to the child abuse/neglect hotline during nonoffice hours. The directive contains definitions for "withholding of medically indicated treatment" and "infant" that accurately restate the Federal standards.[161]

The second directive, dated September 29, 1986, fulfills the Federal mandate that the department establish a list of hospital contact persons. In accord with the Federal regulation, the directive provides that the department will exercise subpoena authority for access to medical records if they are not made available. Also in accord with the Federal rule, the directive provides that an independent medical examination will be obtained by a court order "allowing/requiring such an exam as part of our investigation and efforts to protect a suspected victim of child abuse/neglect."[162]

On their face, the Nebraska procedures appear to comply with the CAA and their implementing regulation.

NEVADA

In Nevada, the Welfare Division in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that there had not been any reports of medical neglect since the CAA took effect.[163]

The agency reported that in developing procedures to implement the CAA, it had consulted with the Nevada medicaid staff; neither medical groups nor disability rights groups were consulted.[164]

The procedures were reviewed for compliance with the Federal regulation implementing the CAA. Definitions in the procedures mirror those of the Federal regulation. The enforcement mechanisms required to be specified in the agency's procedures, involving the manner in which the agency will obtain medical records and court orders for independent medical evaluations, are present.

However, the CPS agency appears to treat the infant care review committee (ICRC) in the hospital against which complaint has been lodged as though it were an independent medical consultant. The procedures state:

> C. INVESTIGATION OF REPORTS OF MEDICAL NEGLECT
>
> . . . .
>
> 4. Treating physician recommends against providing treatment (applicable in Baby Doe cases)
>
> The worker needs to determine by *interviewing the treating physician or by reviewing the recommendations of the hospital review committee* or by using the agency's medical consultant if:
>
> a. The child is irreversibly comatose; or
>
> b. Treatment would merely prolong dying, not be effective in ameliorating or correcting all of the child's life threatening conditions or otherwise be futile in terms of survival of the child; or
>
> c. Treatment would be futile in terms of survival of the child and treatment itself under such circumstances would be inhumane.
>
> If these can be clearly determined to be the case, the investigation can be discontinued. If the above cannot be clearly determined from interviewing the treating physician, the worker should either contact the *hospital review committee,* if one exists, or contact the agency's medical consultant (for Welfare Division cases, contact the Medi-

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[160] Telephone interview with Mona Way, Program Specialist, Division of Human Services (Aug. 8, 1988).

[161] Nebraska Department of Social Services Administrative Directive—Human Services No. 3–86.

[162] Nebraska Department of Social Services Administrative Memorandum—Human Services No. 10–86.

[163] Information obtained from Connie Martin, CPS Specialist, by Commission staff (Aug. 2, 1988).

[164] Letter from Carol Johnston, Acting Assistant Chief, Social Services, to *Issues in Law and Medicine* (Apr. 9, 1987).

> caid Unit in Central Office for the name of the consultant) to help in making the determination.[165]

The clear implication of this statement is that the Nevada CPS agency places an ICRC on a par with the agency medical consultant as the source for a determination whether care is being provided in accordance with the Federal treatment standards. Placing a hospital committee in this role gives rise to a self-evident conflict of interest (see Preface, NOTE B).

Nevada presents a case of a State CPS agency that has for the most part effective investigation and enforcement measures to react to a report of medical neglect of a disabled infant. Notwithstanding, the agency erroneously regards the hospital against which a complaint is lodged as an "independent" medical examiner in such a case.

Although the Nevada standard of care, definition of the class protected, and provisions for obtaining medical records and independent medical examinations comply with the Federal regulation, the State's apparent willingness to defer to infant care review committees at hospitals whose staff is charged with illegal denials of treatment for crucial medical analyses of whether such charges are founded creates a significant failure of compliance.

NEW HAMPSHIRE

In New Hampshire, the Bureau of Children in the Division of Children and Youth Services of the Department of Health and Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that there have been no reports of withholding of medically indicated treatment from infants with disabilities in New Hampshire since 1985.[166]

The agency said that when developing its procedures to implement the CAA, it consulted the ethics committee chairman of Mary Hitchcock Hospital, the only tertiary infant care hospital in the State. The New Hampshire Hospital Association assisted in dissemination of the policy. Disability rights groups were not consulted.[167]

Agency procedures were reviewed for compliance with the Federal regulation implementing the CAA. Definitions presented in the procedures mirror those in the Federal regulation. The enforcement mechanisms required by the Federal regulation to be specified in the agency's procedure, that is, the manner in which CPS will obtain medical records and court orders for independent medical evaluations, are also present.

Although the procedures appear to show that the CPS agency will conduct independent investigations of reports of medical neglect, interviews with the agency staff responsible for protecting the infants raised questions in this regard. The agency's infant medical neglect social worker stated that if a report of medical neglect is received, the opinion of an second physician would be obtained to ensure that the treatment is appropriate. There was no indication that there would be a determination by agency staff about whether the treating or consulting physician was complying with the CAA standard of care. When asked from whom the second opinion would come, the infant medical neglect social worker indicated that the ethics committee at Mary Hitchcock Hospital would review the medical treatment and that, if it gave approval, there would be no further investigation. The staff person also indicated that hospitals in outlying areas call on the Mary Hitchcock ethics committee for advice.[168]

Under the Federal regulation, the existence of an ICRC has no bearing on the duty a State CPS system has to investigate all known or suspected cases of medical neglect. If the agency has delegated to a hospital review committee the authority to determine whether treatment is medically indicated or whether the treatment exceptions are applicable, it has compromised the intent of the statute and is not in compliance with the Federal standards. (See Preface, NOTES A and B.) The Federal regulations are clear that it is the State's CPS system that must make the determination whether treatment is medically indicated under the CAA.

New Hampshire's procedures appear on their face to comply with the CAA and its implementing regulations. However, the practice of deferring the legal question of medical neglect to a hospital ICRC indicates a fundamental misunderstanding of the role of the CPS in enforcing the CAA.

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[165] Welfare Division Service Manual, sec. 417.11(C)(4) (emphasis added).

[166] Telephone interview with Roger Desrosiers, Administrator of Management and Operations, Children's Bureau, Division of Children and Youth Services (July 28, 1988).

[167] Telephone interview with Paul Tamburro, Infant Medical Neglect Social Worker, Division for Children and Youth Services, by *Issues in Law and Medicine* (June 10, 1987).

[168] *Id.*

NEW JERSEY

In New Jersey, the Division of Youth and Family Services in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that since the CAA went into effect there had been three reports of medical neglect, one in 1985 and two in 1986. In all three cases, the investigators found that the complaint was "not substantiated."[169]

When developing procedures to implement the CAA, the agency reported that it consulted with the State attorney general's office, the chief pediatrician at a local hospital, and a disability rights group at Rutgers University.[170]

The agency procedures were reviewed for compliance with the Federal regulation that implements the CAA. The enforcement mechanisms required by the Federal regulation to be specified in the agency's procedure, namely, the manner in which CPS will obtain medical records and court orders for independent medical evaluation, are included.

However, the procedures contain no definition of the term "infant," thus failing to describe the class they protect. In response to a draft of relevant portions of the Commission report, the director of the Division of Youth and Family Services addressed this criticism. He conceded that the agency's procedures did not define the term "infant," but contended that such a definition was unnecessary because "[e]xisting protections available under present New Jersey statutes. . .define any person from birth to eighteen years of age and would include all children under and over one year of age." This argument fails to recognize that the general standards concerning medical neglect for all children are dramatically less detailed and precise than those the CAA make applicable to "disabled infants with life-threatening conditions." (See Preface, NOTE E.)

The procedures also contain no definition of the term "withholding of medically indicated treatment," thus failing to establish the standard of care required. The agency states that "[t]he New Jersey statute which specifically addresses the issue of failure to supply a child with adequate medical care was seen as adequately defining standards of medical neglect which would include the withholding of medically indicated treatment." Examination of this statute revealed that there is no explanation of withholding of medically indicated treatment offered other than "failure of. . .a parent or guardian,. . .in supplying medical or surgical care. . . ."[171] This falls significantly short of the detail contained in the meticulously negotiated CAA standard of care. (See Preface, NOTE F.)

The agency appears to have contracted with two independent pediatricians to assist the CPS worker in determining whether treatment is legally required:

> Upon receipt of a referral, the appropriate regionally based supervisor or Senior Investigator will be contacted along with the pediatric consultant. The pediatric consultant will contact the person named by the facility as their Baby Doe contact as specified by the federal regulations governing this act. The consultant will review the child's condition and make an appointment to initiate an on-site investigation if it is indicated.[172]

Although, on their face, the New Jersey procedures otherwise appear to comply with the CAA and their implementing regulation, the failure of the procedures to define either the standard of care or the class the standard protects constitute a significant lack of compliance.

NEW MEXICO

In New Mexico, the Social Services Division in the Human Services Department is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it has not received any reports of medical neglect of an infant with a disability since the CAA went into effect. The agency also reported that procedures for the investigation of a report of medical neglect were created with the help of the University of New Mexico Hospital; no disability rights groups were consulted.[173]

The State agency's policies and procedures were reviewed for compliance with the Federal regulation that implements the CAA. Enforcement mechanisms that are required by the Federal regulation to be specified in CPS agency procedures are included in a memorandum issued by the main office to agency staff. These include a description of the manner in which the agency will obtain an infant's medical records and a court order for independent medical evaluation. Also included in this memorandum are definitions for "withholding of medically indicated treatment" and for "infant in accordance with the federal regulation." When the agency's most recent procedures manual was reviewed, these provisions had been incorporated.

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[169] Telephone interview with Constance Ryan, Coordinator, DYFS Medical Unit, Division of Youth and Family Services (Aug. 17, 1988).

[170] Telephone interview with Sue McGrory, Supervisor, Institutional Abuse Unit, Division of Youth and Family Services, by *Issues in Law and Medicine* (June 24, 1987).

[171] N.J. Stat. Ann. §9:6–8.9. (West Supp. 1988)

[172] Division of Youth and Family Services, Procedures for the Investigation of Baby Doe Cases in New Jersey.

[173] Telephone interview with Judy Mayhon, Planner, Social Services Division, Program Services Bureau, New Mexico Human Services Department, by *Issues in Law and Medicine* (June 4, 1987).

However, the New Mexico CPS agency abdicates its responsibility to determine whether the law is being followed to those alleged to be violating the law, contrary to the requirements of the Federal regulation that the CPS must make the determination whether treatment is medically indicated under the CAA (see Preface, NOTE A). The procedure states that a report is "unsubstantiated when. . .the parents and the treating physician are in agreement that medical treatment should be withheld from the infant."[174] Nowhere in the procedure is there mention of an independent medical consultant to be available to review all reports of medical neglect and to determine if the decision falls below the Federal standard of care. Instead, the hospital that is the subject of a complaint is given the responsibility to review the case or to serve as the equivalent of an independent medical examiner.

To refuse to investigate a report of medical neglect because there is no disagreement on treatment between the parents and the attending physicians blatantly flouts the intent of the CAA to create an enforcement mechanism for the protection of a disabled infant's right to treatment. The New Mexico procedures clearly run counter to the CAA's requirement that the CPS agency serve as the independent investigating authority to ensure that the Federal standard of care is provided to the infant with a disability.

Although its policies are in place, New Mexico is out of compliance with the CAA and their implementing regulation in considering any report unsubstantiated when the physician and parents agree to withhold treatment.

NEW YORK

The New York Division of Family and Children Services of the Department of Social Services is the State agency responsible for the enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that there had been two cases of denial of medically indicated treatment to disabled infants reported since the regulation went into effect.[175] In response to a followup inquiry by the Commission, the agency reported that it was impossible to distinguish reports of medical neglect of infants with disabilities from reports of "lack of food" or "lack of medicine" categories and was therefore unaware of whether there had been any cases within the State.[176]

The agency reported that it did not find it necessary to establish any new regulations and procedures for implementation of the CAA because it thought that present mechanisms were sufficient. Therefore, no consultation with outside groups took place.[177]

New York's failure to promulgate rules specifically implementing the CAA regulations has resulted in clear violations of Federal requirements. Federal regulations require that a State CPS develop written procedures with regard to medical neglect reports, specifying the manner in which it will obtain the child's medical records. These appear to be absent. (See Preface, NOTE C.) The regulation requires written procedures under which the CPS agency may obtain a court order for an independent medical examination of an infant. The New York procedures should make explicit provision for court-ordered, independent examinations. (See Preface, NOTE D.) The definition of such terms as "infant" and "withholding of medically indicated treatment," essential to establish the standard of care and the class of those protected by it, do not appear in any of the agency's materials. (See Preface, NOTES E and F.)

Because no specific procedures were established to respond to a medical neglect situation, there is no method for obtaining an independent medical consultant to conduct the examination, review the medical records, or otherwise assist the CPS worker in evaluating a report of medical neglect. In fact, an agency staff person indicated that there were no specific guidelines indicating who should be consulted should a medical neglect situation arise. She stated that possibly the independent consultant would be another doctor within the hospital if it was a large facility.[178] It is possible, therefore, that a New York CPS worker would be relying for critical evaluations solely on personnel at the hospital against which the complaint is lodged. A letter from the deputy commissioner of the Division of Family and Children's Services to district CPS officials states:

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[174] New Mexico Human Services Department, Social Services Procedure §4.8.3.1, §4.8.3.2.(1).

[175] Telephone interview with Sally Perry, Division of Family and Children Services, by *Issues in Law and Medicine* (June 24, 1987).

[176] Telephone interview with Sally Perry, Division of Family and Children Services, and Patty O'Donnell, Assistant Director, New York State Child Abuse Hotline (Aug. 9, 1988).

[177] Information obtained from Sally Perry, Division of Family and Children Services, by *Issues in Law and Medicine* (June 24, 1987).

> While CPS will need to rely heavily upon the judgment of the physicians involved in the case (including in some instances newly established hospital based Infant Care Review Committees, recommended by the federal regulations) the CPS caseworker and supervisor will need to be capable of sorting out some particularly complex issues, involving medical, legal and ethical areas where no societal consensus has been reached.[179]

In short, the State of New York has not complied with the Federal legal requirements that it establish specific and identifiable enforcement mechanisms for the response to a report of the denial of medical treatment to a handicapped infant. It is substantially out of compliance with the Child Abuse Amendments.

NORTH CAROLINA

In North Carolina, the Division of Children's Services in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that there had been no reported cases of medical neglect of infants with disabilities since the 1985 Federal law was passed.[180]

In developing procedures for implementation of the CAA, the agency reported that "[r]epresentatives from the four teaching hospitals in the state and the State Council on Developmental Disabilities as well as other related state and local agencies were a part of our planning process throughout the process. . . ."[181]

The procedures were reviewed for compliance with the Federal regulation that implements the CAA. The definitions of terms correctly reflect the Federal standards. In accord with the Federal regulations, the procedures specify the manner in which the agency will obtain access to medical records and other pertinent information and will obtain court orders for independent medical examinations.

However, the North Carolina procedures fail to specify a method for obtaining an independent third-party medical expert to assist the CPS worker in evaluating a report of medical neglect. Instead, the procedures state:

> Because of the complex nature of the medical conditions that an infant might have, medical consultation will be needed in conducting the investigation. *The hospital or health care facility staff in which the infant is receiving care will, in most cases, be the primary resource for that consultation.*[182]

In other words, the facility being investigated is made the "primary resource" for "consultation" about whether it is engaged in illegal denial of treatment. This approach, with its obvious conflict of interest, significantly undermines the responsibility of the CPS agency to conduct an effective arms-length investigation to ensure that the rights of infants with disabilities to receive legally mandated treatment are respected. The independence and effectiveness of North Carolina investigations would be substantially improved were the agency to establish procedures for the use of an independent third-party medical consultant, selected with input from disability rights groups, to assist the CPS worker in all nonfrivolous cases.

NORTH DAKOTA

In North Dakota, the Children and Family Services Division in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

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[178] *Id.*.

[179] Letter from Joseph Semidei, Deputy Commissioner, Division of Family and Children Services, to CPS District Officers (Oct. 4, 1985). This letter evinces a dismaying failure to recognize that the standard of care established by the Child Abuse Amendments, enacted by an overwhelming vote, should be treated as constituting the "social consensus" by the agency charged with its enforcement.

[180] Telephone interview with Alice Coleman, CPS Program Consultant, Division of Social Services (July 21, 1988).

[181] Letter from Mary Lee Anderson, Program Manager, Child Protective Services, Division of Social Services, to *Issues in Law and Medicine* (May 29, 1987).

[182] North Carolina Division of Family Services, Family Services Manual, vol. I, ch. VIII Medical Neglect of Disabled Infants with Life Threatening Conditions (emphasis added).

The agency stated that it had one report of medical neglect of a infant with a disability since the regulation went into effect.[183]

The agency reported that during the development of agency procedures concerning report of medical neglect, it consulted with the Health Department's Maternal and Child Health Division, the North Dakota chapter of the American Academy of Pediatrics, and the University of North Dakota Children and Family Services Training Center.[184]

The North Dakota procedures were reviewed for compliance with the Federal regulation that implements the CAA. The enforcement mechanisms that are required by the Federal regulation to be specified in the agency's procedures, namely, the manner in which CPS will obtain medical records and court order for independent medical examinations, are present. In addition, the procedures provide for an independent medical consultant to be available to provide assistance to the CPS worker at each phase of the investigation. The definition of the standard of care is given in the manual and conforms to the Federal regulation. However, there is no definition of "infant," the class protected. (See Preface, NOTE E.)

Apart from the significant omission of a comprehensive definition of the class protected, the North Dakota procedures appear, on their face, to comply with the CAA and their implementing regulation.

OHIO

The Ohio Bureau of Children's Protective Services in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that its office had "received two calls since the amendment became effective in October 1985. Both calls were determined to not fit the criteria necessary to be considered reports of withholding medically indicated treatment from disabled infants."[185] The agency confirmed in response to a followup inquiry that these had been the only reports to the agency.[186]

The agency reported that the procedures that it established to respond to reports of medical neglect of disabled infants "were written in cooperation with a committee of medical professionals." There is no indication that disability rights groups were consulted.[187]

The procedures were reviewed for compliance with the Federal regulation that implements the CAA. The agency recognizes that it alone has responsibility to determine the question of medical neglect of a disabled infant:

> The PSCA (Public Children's Services Agency) shall investigate all reports which allege that a disabled infant with life-threatening conditions is a neglected child due to the withholding of appropriate nutrition, hydration, medication, or medically indicated treatment. This investigatory responsibility may not be delegated to any other public or private agency or organization.[188]

In accord with the Federal regulations, the procedures contain enforcement mechanisms that specify the manner in which the agency will obtain access to medical records and secure court orders for independent medical examinations. Also present in the procedures is a detailed method for obtaining an independent medical consultant to conduct the examination, review the medical records, or otherwise assist the CPS worker. The agency reported that it had "developed an on-call system, in operation 24 hours a day, 7 days a week, which has workers with the Bureau of Children's Protective Services and medical consultants available to assist the local agencies."[189]

However, the procedures contain an underinclusive definition of the term "infant." The procedures define "disabled infant" to mean "a child less than 1 year of age who has a physical or mental handicap which substantially limits or may limit in the future one or more major life activities such as self-care, receptive and expressive language, learning and mobility."[190] Limiting enforcement of the CAA solely to the class of children under 1 year of age is underinclusive with respect to those that were intended to be protected by Congress under the CAA.

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[183] Telephone interview with Gladys Cairns, Children and Family Services Division (July 20, 1988).

[184] Telephone interview with Gladys Cairns, Children and Family Services Division, by *Issues in Law and Medicine* (June 12, 1987)

[185] Letter from Jean Schafer, Chief, Bureau of Children's Protective Services, to *Issues in Law and Medicine* (Apr. 2, 1987).

[186] Telephone interview with Georgia McGill, Social Program Developer, Bureau of Program Policy (July 22, 1988).

[187] Letter from Jean Schafer, Chief, Bureau of Children's Protective Services, to *Issues in Law and Medicine* (Apr. 2, 1987).

[188] Ohio Administrative Code §5101:2-35-77(F) (1987).

[189] Letter from Jean Schafer, Chief, Bureau of Children's Protective Services, to *Issues in Law and Medicine* (Apr. 2, 1987).

[190] Ohio Administrative Code §5101:2-35-76(F) (1987).

In a letter of October 11, 1988, the agency, commenting on a draft of relevant portions of the Commission report, addressed this criticism. The agency did not deny that the quoted agency rule limits the application of the term "disabled infant" to those under one year. Instead, it pointed out that other provisions in the agency code provide protections against medical neglect of "handicapped person[s]" under 21 years.[191] While this is accurate, it fails to recognize that the general provisions defining medical neglect are significantly less detailed and specific than those in the CAA standard of care, which the Federal regulation specifically makes applicable to certain categories of infants older than 1 year (see Preface, NOTE E).

Although it received grants under the Child Abuse Prevention and Treatment Act in prior years, Ohio did not receive such a grant in fiscal year 1988,[192] and thus was not legally subject to the requirements of the CAA. However, with the significant exception of an underinclusive definition of the class of those protected, the Ohio procedures on their face appear to comply with the CAA and their implementing regulation.

OKLAHOMA

The Oklahoma Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In the development of procedures to implement the CAA, the agency reported that neither Children's Hospital of Oklahoma nor disability rights groups were consulted.[193]

The agency reported that there had been three cases of medical neglect reported since 1985. The first, in January 1985, was "ruled out" and the child died a month later. In the second, in November 1985, a child was placed in the agency's custody, received treatment, but died later. In July 1986, the agency placed another child in its custody and required that the child be treated. The staff person stated that this child is alive today.[194] In response to a more recent inquiry, the agency reported that these were the only cases concerning medical neglect of disabled infants in which the agency has been involved.[195]

Agency procedures were reviewed for compliance with the Federal regulation that implements the CAA. They were found to be short, consisting of less than a page, and missing provisions that are required by Federal law for agency compliance. The procedures cite for their authority previous Federal regulations under section 504 that are without present effect and make no mention of the agency's responsibilities under the CAA and the Federal regulation that implements it.

The procedures fail to fulfill the Federal regulatory requirements that the agency specify in writing the manner in which it will obtain medical records of the child (see Preface, NOTE C) and that the CPS agency specify in writing the manner in which it will obtain a court order for an independent medical examination of the infant (see Preface, NOTE D). Also missing from procedures is any definition of the term "infant" or the term "withholding of medically indicated treatment" (see Preface, NOTES E and F).

The procedures are silent with respect to the use of an independent third-party medical examiner. Instead, the agency informed the Commission that it would make use of hospital-based infant care review committees.[196] This practice is an abdication of authority to the very hospital whose staff is alleged to be denying legally required treatment. The Federal regulations are clear that it is the State's CPS system that must make the determination whether treatment is legally required under the CAA and whether circumstances exist to invoke the power of the State. (See Preface, NOTES A and B.)

The Oklahoma CPS agency has not developed procedures that remotely attempt to comply with present regulations under the CAA. Further, the agency has abdicated its responsibility to investigate, effectively delegating it to the hospital infant care review committees which are to be investigated.

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[191] Letter from Georgia NcGill, Social Program Developer, and Dora Sterling, Supervisor, Policy Development Unit, Ohio Department of Human Services, to T. Burke Balch, Office of General Counsel, U.S. Commission on Civil Rights (Oct. 11, 1988).

[192] Telephone interview with Mary McKough, Program Analyst, National Center for Child Abuse and Neglect, Office of Human Development Services, Department of Health and Human Services (Dec. 2, 1988).

[193] Telephone interview with Diana Stell, Program Field Representative, Department of Human Services (July 6, 1987).

[194] *Id.*

[195] Telephone interview with Diana Stell, Program Field Representative, Department of Human Services (July 27, 1988)

[196] *Id.*

OREGON

In Oregon, the Children's Services Division in the Department of Human Resources is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that as of 1987 there had been only one reported case of withholding of medically indicated treatment from an infant with disabilities.[197] In response to a followup inquiry, the agency reported that there had been an additional case, but it was not truly a report of medical neglect. The hospital had requested State neonatologists to confer with them about an infant born with only 2 inches of intestine. All parties agreed that there was nothing that could be done and the child died.[198]

The agency reported that "[e]xtensive contact with the medical community was utilized in developing Oregon's implementation of the Child Abuse Amendments of 1984 (CAA)."[199] The agency gave no indication that disability rights groups were consulted.

Agency procedures were reviewed for compliance with the Federal regulation that implements the CAA. Although the definition of "withholding of medically indicated treatment" conforms to the Federal regulation, the definition of "infant" does not; it applies only to those "less than one year of age."[200] As required by the Federal regulation, the agency's manual specifies the manner in which it will obtain medical records and a court order for an independent medical examination. The manual also includes a detailed methodology for an independent medical consultant to conduct the medical examination, to review the medical records, or otherwise to assist the CPS worker. The agency reported that it had the assistance of five neonatologists from teaching hospitals in the State to serve in this role.[201]

The Oregon procedures appear to recognize that a report may be against either a parent for refusal to consent or against a medical provider for a recommendation against treatment. The agency is to take custody of the child in either instance if the medical examiner finds that treatment is indicated. The case worker is instructed to assist the parent with referrals to support groups, community educational resources, agencies that provide services for disabled infants and their families, and agencies with financial resources for medical and rehabilitative services.

The agency procedures contain a number of apparent weaknesses. Although the definition of "medically indicated treatment" properly makes clear that "appropriate nutrition, hydration, and medication" must be provided even when one of the three exceptions to the general requirement of treatment is applicable,[202] the procedures themselves direct that "the investigation shall be terminated and the case closed" when a hospital review committee (HRC) decides whether treatment is medically indicated:

> Grounds for overriding the refusal of the parents of the infant to consent to medical care and treatment exist only if any reasonable medical judgement would be that treatment is medically indicated. *The parents' refusal to consent shall be respected if the Review Committee, if any,* and a consulting physician finds that treatment is not medically indicated.[203]

And further in the rule the agency instructs:

> If the infant's parents do not desire medical treatment beyond that being provided by the treating physician and *if the reasonable medical judgement of HRC and other consulting medical professionals* is that medically indicated treatment is being provided, the Medical Neglect Investigator will document this agreement in the case record. The CPS worker will close the case and take no further action.[204]

It is unclear from the face of the policy whether the "consulting physician" is to be another doctor at the same hospital or whether this reference is meant to point to the CPS consultant neonatologist. In either case, it is clear from the face of the procedures that a HRC has been given a stake in decisionmaking. Federal regulations are clear that it is the CPS agency alone that makes the decision whether treatment (or nontreatment) is appropriate. This practice subverts the intent of the CAA to create a strong enforcement mechanism for the defense of infants with disabilities. (See Preface, NOTES A and B.)

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[197] Letter from Robert Pinkerton, Manager of National Center for Child Abuse and Neglect Grants, Children's Services Division, to *Issues in Law and Medicine* (Mar. 30, 1987).

[198] Telephone interview with Robert Pinkerton, Manager of National Center for Child Abuse and Neglect Grants, Children's Services Division (July, 22, 1988).

[199] Letter from Robert Pinkerton, Manager of NCCAN Grants, Children's Services Division, to *Issues in Law and Medicine* (Mar. 30, 1987).

[200] Children's Services Division, Client Services Manual I, Rule I-B.2.2.2 (Definitions 412-61-004 (3)) (1986). *Cf.* Preface, NOTE E.

[201] Letter from Betty Uchytil, Assistant Administrator, Office of Family Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Sept. 29, 1988).

[202] Children's Services Division, Client Services Manual I, Rule I-B.2.2.2 (Definitions 412-61-004(9)).

[203] Children's Services Division, Client Services Manual I, Rule I-B.2.2.2(C)(3)(a)(1) (emphasis added).

[204] *Id.*, Rule I-B.2.2.2(3)(C) (emphasis added).

In a letter dated September 29, 1988, the agency commented on a draft of relevant portions of this report and addressed the above concern. The assistant administrator of the Office of Family Services assured the Commission that:

> The Medical Neglect Investigator determines the course of action to be taken including whether or not there should be court involvement. Information is obtained from the attending physician, the hospital review committee, the consulting neonatologist and other appropriate medical professionals, but the Medical Neglect Investigator is the one responsible for deciding if legally required treatment is being withheld.

Despite the construction this response puts on this provision in the procedures, the Commission believes that the procedures can be interpreted to allow an inappropriate amount of authority to the hospital review committee on the question whether treatment is medically indicated that can allow the real responsibilities of the CPS to remain unclear at critical junctures.

RHODE ISLAND

In Rhode Island, the Division of Child Protective Services in the Department of Children and Their Families is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that only one report of medical neglect of an infant with a disability had been received since the effective date of the CAA.[205]

The agency was unable to say whether medical or disability rights groups were consulted when its procedures were developed.[206]

The procedures were reviewed for compliance with the Federal regulation that implements the CAA. The definitions of terms correctly reflect the Federal standards. In accord with the Federal regulations, the procedures specify the manner in which the agency will obtain access to medical records and other pertinent information and the manner in which it will obtain court orders for independent medical examinations.

The Rhode Island procedures do not specify the method for obtaining an independent third-party medical expert to assist the CPS worker in evaluating a report of medical neglect. The procedures merely state:

> II. *PROCEDURE*
>
> . . . .
>
> D. The CPI [Child Protection Investigator] and the "Baby Doe" Coordinator will discuss the situation prior to the initiation of the investigative process.
>
> E. The Department must investigate the allegation(s) in accordance with standard procedures for the investigation of child abuse/neglect.
>
> F. The "Baby Doe" coordinator will contact the individual designated by the appropriate hospital to gather preliminary case information. The Coordinator and CPI will discuss the situation prior to initiating legal proceedings.
>
> G. The CPI will contact the Department's Legal Counsel to initiate the necessary legal proceedings to obtain an independent medical examination, to gain access to medical records, or to seek a court order for medical/surgical treatment.[207]

Notwithstanding a reference in the procedures for a court order for an independent medical examination, there is no mention of any method for obtaining an independent medical consultant to do the examination, review the medical records, or otherwise assist the CPS worker. The medically untrained CPS worker appears to be alone in determining whether the health care facility is providing appropriate treatment. In effect, the procedures appear to authorize the CPS worker to rely in some cases solely on the medical information received from the hospital against which the complaint was lodged.

The most serious weakness in the procedures, however, is that they appear to address only situations in which parents do not wish to provide treatment despite the advice of the child's physician. The procedures call for intervention in only one set of circumstances:

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[205] Telephone interview with Jo Ann Loher, Policy and Planning Manager, Division of Child Protective Services (July 21, 1988).

[206] Telephone interview with Kenneth Fandetti, Division of Child Protective Services, by *Issues in Law and Medicine* (June 30, 1987).

[207] Department for Children and Their Families, Procedure for Medical Neglect of Infants with Life-Threatening Disabilities, No. 428 at 3.

> The Department shall immediately intervene upon receipt of a report that parents refuse, despite the advice of their physician, to consent to further evaluation by a specialist or to the transfer of their infant to a more specialized facility. In responding to reports of medical neglect, the Department is responsible for coordination and consultation with individuals designated by each hospital. This communication can help to diminish disruption to the hospital and the family during the course of the child protective investigation.[208]

There appears to be no specific provision for investigation of a report of a case in which a physician, with or without the concurrence of the parents, is denying legally required treatment.

Despite their apparent technical compliance with the CAA in a number of respects, the Rhode Island procedures do not appear to be designed to address the most typical circumstance in which treatment is denied: at the instance of the child's physician. They also provide for the CPS worker to place undue reliance on the judgment of the health facility where neglect is alleged to be occurring. The effectiveness of any investigation to discover if legally mandated treatment is being denied would be significantly improved were the agency to specify procedures for the use of an independent third-party medical consultant, selected with the benefit of advice from disability rights groups, to assist the CPS worker in all nonfrivolous cases.

SOUTH CAROLINA

In South Carolina, the Child Protective and Preventive Services in the Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

Upon inquiry, the agency stated that it had not received any reports of medical neglect of infants with disabilities since the regulations went into effect.[209]

The agency reported that when developing policies for the implementation of investigative procedures, it had "established a Task Force comprised of representatives from the medical profession, legal consultants and hospital association to develop the policy and procedures."[210] There was no indication that disability rights groups were consulted.

These procedures were reviewed for compliance with the Federal regulations that implements the CAA. The definitions of terms correctly reflect the Federal standards. In accord with the Federal regulations, the procedures specify how the department will obtain access to hospital records and how it will obtain court orders for an independent medical examination and treatment. In addition, agency procedures also present a detailed method for investigation by an independent medical consultant to conduct an examination, review the medical records, or otherwise assist the CPS worker. The procedures indicate that the medical consultants will be neonatologists from tertiary unit hospitals, and it is specified that these consultants will not investigate in the region where they practice. The procedures assume the agency will make the determination of medical neglect: "The Department of Social Services will make the case determination based on the findings of the medical consultant, interviews with the parents, and if necessary, collateral contacts with other appropriate individuals"[211]

On their face, the South Carolina procedures appear to comply with the requirements of the CAA and their implementing regulation.

SOUTH DAKOTA

In South Dakota, the Child Protection Services Unit in the Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it had not received any reports of medical neglect of disabled infants.[212]

The agency reported that it had consulted with "medical specialists" in the development of procedures to implement the CAA. The agency described no contact with disability rights groups.[213]

The procedures were reviewed for compliance with the Federal regulations that implement the CAA. The definition of the term "withholding of medically indicated treatment" in the procedures is consistent with the Federal regulation. Enforcement mechanisms that are required to be specified in CPS agency procedures, such as the manner in which a CPS will obtain medical records and a court order for independent medical examination, are also set forth. In addition, South Dakota ensures that an independent medical consultant, not affiliated with the hospital or a resident of the area, will conduct the examination, review the medical records, or otherwise assist the CPS worker. However, the procedures include no definition of the term "infant." An accurate definition that corresponds with the Federal regulation should be incorporated into the State's procedures to provide notice to agency personnel, parents, and medical providers of the class of those protected by the detailed Federal treatment standards. (See Preface, NOTE E.)

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[208] Department for Children and Their Families, Policy for Medical Neglect of Infants with Life-Threatening Disabilities, No. 428 at 2.

[209] Letter from Marguerite Campbell, CPPS Consultant, Child Protective and Preventive Services to Vincent A. Mulloy, Office of the General Counsel, U.S. Commission on Civil Rights (July 21, 1988).

[210] Letter from Pamela Bond, Project Adminstrator, Child Protective and Preventive Services and Shirley Fitz-Ritson, Director, Child Protective and Preventive Services, to *Issues in Law and Medicine* (Apr. 2, 1987).

[211] Medical Neglect of Disabled Infants, Procedures, South Carolina Department of Social Services, sec. XVIII.

[212] Telephone interview with Merlin Weyer, Program Specialist, Child Protection Services (July 28, 1988).

[213] Letter from Merlin Weyer, Program Specialist, Child Protection Services, to *Issues in Law and Medicine* (Apr. 28, 1987).

The South Dakota procedures contain a curious and cumbersome method of case review when a hospital has an infant care review committee. The agency appears to have made an attempt to involve the committee in the determination of whether a report of medical neglect is "substantiated." The directive states:

> *IF THE INFANT IS IN A HOSPITAL WITH AN ICRC*, the medical consultant will contact the ICRC representative to discuss the referral. All allegations should be presented to the ICRC representative. If the ICRC is aware of the infant and if both the ICRC representative and the medical consultant agree with the treatment/care being provided, the referral will be considered unsubstantiated and the case will be closed. If the ICRC is not aware of the infant, the ICRC will be requested to review the case. The findings of the ICRC as to the appropriateness of care provided will be reviewed by the medical consultant and if he is in agreement it will be accepted by the Department. If it is decided by the medical consultant that the care is not appropriate, but the ICRC is able to institute proper care, no further action will be required. However if the ICRC is not able to ensure adequate care as determined by the medical consultant, the medical consultant shall immediately contact one of the listed State Office representatives who will contact the States Attorneys Office so that appropriate legal action may be taken. The ICRC is to be notified of such action. Appropriate legal action may consist of a court order ordering an independent medical examination of the infant or an order requiring medical treatment.[214]

These provisions are not as egregious an abdication of agency authority as those in other States that completely defer to the views of an ICRC, because an agency medical consultant has the final word. However, the procedures appear to go beyond the consultation with an ICRC, which HHS has recognized as proper, to an unwarranted integration of a committee of the very hospital that is being investigated into the agency decisionmaking process. The agency's deference is inappropriate because Federal regulations clearly require the State's CPS system to make the determination whether treatment is medically indicated. (See Preface, NOTES A and B.)

In a number of respects, the procedures in effect in South Dakota are in compliance with the CAA. However, the effectiveness of any medical neglect investigation would be substantially improved by correction and clarification of the CPS relationship with the ICRC. In addition, the definition of "infant" found in the Federal regulations should be added to the South Dakota procedures.

TENNESSEE

In Tennessee, the Child Protective Services Unit within the Division of Social Services in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that there had been no reports of medical neglect of infants with disabilities made to the agency since the regulation went into effect.[215]

The agency reported that it had created the policy without the assistance of any outside organization and that it had an agreement with Vanderbilt Hospital to provide instruction to CPS staff across the State.[216]

The agency's policies and procedures were reviewed for consistency with the Federal regulations that implement the CAA. They state:

> II. *Policy*
>
> The Department of Human Services will accept and investigate all reports which allege that a disabled infant is being deprived of nourishment and/or medically beneficial treatment solely on the basis of his/her present or anticipated mental or physical impairment.

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[214] Child Protective Services Procedures Manual, at 79.

[215] Telephone interview with Pat Overton, Director, Child Protective Services, by Commission staff (July 20, 1988).

[216] Information obtained from Gloria Manhein, Director, Child Protective Services, by *Issues in Law and Medicine* (July 13, 1987).

> The Department will take appropriate action to prevent further unlawful medical neglect of such children.[217]

Enforcement mechanisms, such as the method by which CPS staff will obtain the infant's medical records or the method by which the agency will obtain a court order for an independent medical examination for the infant, are not specifically spelled out in the neglect of handicapped infants section of the policy. However, the agency can demonstrate its ability to perform these requirements within the general Child Protective Service policy.

However, no definition of the term "infant" is given in the policy. This is a significant deficiency. (See Preface, NOTE E.) A definition of the term "withholding of medically indicated treatment" is also absent from the procedures. Instead, it appears that the the following is the medical treatment standard the agency uses to determine whether treatment is appropriate:

> F. *Decision Making*
>
> After talking with the parents, medical personnel, ICRC, and the Child Abuse Review Team, the staff must decide which action to take. It is possible to seek a court order to require medical treatment of an infant. However, the following test must be met before taking such action:
>
> > "Is a health care provider, solely on the basis of present or anticipated physical or mental impairments of an infant, withholding medical treatment or nourishment from the infant, who in spite of such impairments would medically benefit from the treatment or nourishment?"
>
> If after investigation and consultation, the counselor reasonably believes or suspects the above test has been met, he/she should prepare a legal referral to seek court ordered medical treatment. If the test has not been met then the case should be closed.[218]

This definition seems more appropriate to enforcement of section 504 than of the CAA. To comply with the CAA, an agency must employ the legal standard of care it contains, a legal provision scrupulously crafted by Congress to establish only narrow circumstances in which maximal treatment may legally be withheld. (See Preface, NOTE F.)

To the Tennessee agency's credit, a systematic and objective approach to investigating a report of medical neglect is stated by the procedures. The procedures call for interviews with the parents, medical personnel, the hospital's ICRC, and an entity that apparently reviews all reports of medical neglect:

> D. *Child Abuse Review Team Staffing*
>
> These cases must be brought to the Child Abuse Review Team for their recommendations. This is appropriate since the Team is an independent review committee with medical professionals.[219]

The agency reported that this was a panel composed of medical professionals.[220]

In some respects, the procedures in effect in Tennessee are in compliance with the CAA. However, the agency regulations do not properly define the terms "infant" and the terms "withholding of medically indicated treatment." Both of these terms are absolutely necessary to ensure that the CPS agency make appropriate determinations concerning whether the medical treatment of children who are the subject of a report is in accord with Federal standards.

TEXAS

In Texas, the Protective Services for Families and Children in the Department of Human Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that in developing procedures for enforcement of the CAA, "the Department consulted with various public and private groups including the Texas Hospital Association, Texas Medical Association, Texas Perinatal Association, and the University of Texas School of Nursing." The agency gave no indication that it had consulted any disability rights groups.[221]

The agency reported that:

> Since October, 1985, one report has been received by TDHS [Texas Department of Human Services] indicating withholding of medical treatment of a 5-year old severely handicapped child. Due to the child's extreme disabilities, the parents voluntarily relinquished parental rights to the Department. The child has required repeated hospitalization due to pneumonia, and, the medical facility where the child had previously been taken requested permission from the Department to stop treatment. The Department requested the hospital convene an ICRC to review the

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[217] Department of Human Services, Child Protective Services Manual, vol. IV, app. I, Cases Involving Failure To Provide Nourishment and Medically Beneficial Treatment of Disabled Infants with Life Threatening Conditions at 2.

[218] *Id.* at 4

[219] *Id.* at 3.

[220] Telephone interview with Pat Overton, Director, Child Protective Services (July 20, 1988).

[221] Letter from David Brock, Texas Department of Human Services, to *Issues in Law and Medicine* (Apr. 3, 1987).

child's situation, but the facility did not comply; consequently, the child was simply moved to another hospital where appropriate treatment was obtained. The child continues to receive treatment from this facility without difficulty.[222]

The Texas procedures were reviewed for compliance with the Federal regulation implementing the CAA. Enforcement mechanisms required by the Federal regulation to be specified in CPS agency procedures, such as the manner in which a CPS agency will obtain medical records and court orders for independent medical evaluations, are appropriately included. A definition of "withholding of medically indicated treatment" is included that correctly states the Federal standard. However, there is no definition of the term "infant." This is a serious deficiency.[223]

The Texas procedures technically comply in most respects with the CAA, but other clauses disclose flaws. For example, immediately following the definition of "withholding of medically indicated treatment," the procedures state:

> If the Department receives a report alleging medical neglect consistent with the above definition and involving allegations against the medical facility or medical personnel, the focus of the investigation is to make sure that the parents or other caretakers authorized to consent to medical treatment have been provided with all reasonably available information regarding possible medical treatment or resources for the child.[224]

This instruction undermines the concept that there are medical treatment standards in effect that are to be enforced by the State CPS, implying that a decision to deny treatment in violation of the legally mandated standard of care will not be disturbed if it is "informed." Moreover, despite the policy's statement that CPS must ensure that "all reasonably available information" is to be made available, the procedures do not specify the method for obtaining an independent third-party medical expert to assist the CPS worker in evaluating a report of medical neglect. The procedures merely state:

> 6. If an independent medical examination appears necessary to assure an appropriate resolution of a report of medical neglect, staff must determine whether an independent medical opinion is available. Resources for payment of such an examination include the parents (directly or through insurance), medical schools or other community medical resources, county funds or Title IV-B funds.[225]

Perhaps the most disturbing indication of this agency's attitude toward reports of medical neglect of handicapped infants is in a statement made by a Texas CPS administrator to Commission staff. When asked if there had been any reports of withholding medically indicated treatment in the State of Texas in the last year, he replied that there had not and described this form of medical neglect as a "misunderstood issue caused by an extraordinary event in Bloomington, Indiana. This is primarily an issue related to parents' and physicians' decisions concerning treatment of the child—it is a medical issue, not a political issue."[226]

Apart from the significant omission of a definition, Texas procedures are in most respects in technical compliance with the CAA. However, the agency appears ambivalent toward its responsibility to carry out the terms of the CAA. Furthermore, the effectiveness of any investigation to discover if treatment is legally appropriate would be substantially improved were the agency to specify the use of an independent third-party medical consultant (selected with the benefit of advice from disability groups) to participate in the investigation.

UTAH

The Utah Division of Family Services in the Department of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency states that it has never received a report alleging the withholding of medically indicated treatment from an infant with disabilities. The staff person interviewed by Commission staff volunteered that he was not surprised that there had not been reports of denial of treatment to disabled infants because "a 'Baby Doe' situation would most likely result in a collusion between the parents and the physician. We would have to depend on someone else in the intensive care unit to report denial of treatment to handicapped infants."[227] To cultivate such sources, the staff person reported that his office attempts to meet with staff in Utah's tertiary unit hospitals at least once a year to inform them of their obligation to report these cases.[228]

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[222] *Id.*

[223] In a letter dated Oct. 5, 1988, the assistant commissioner for Protective Services for Families and Children Branch, responding to relevant portions of the Commission's draft report, acknowledged that "[i]t is correct that Texas does not define the term 'infant' in either the Texas Family Code or the Texas Department of Human Services Child Protective Services Handbook."

[224] Texas Department of Human Services, Memorandum from James Marquart, Assistant Commissioner, Protective Services for Families and Children Branch, to Regional Directors for Families and Children at 2.

[225] *Id.* at 3.

[226] Telephone interview with David Brock, Texas Department of Human Services (July 29, 1988).

Procedures to implement the CAA were developed by "an Advisory Committee composed of professionals in Child Protective Services and a local pediatrician specializing in neonatology."[229] Disability rights groups do not appear to have been consulted in the development of these procedures.

The procedures were reviewed for consistency with the Federal regulation that implements the CAA. The enforcement mechanism to obtain medical records from the hospital is set forth in the procedures. However, the Utah procedures inaccurately restate two critical definitions of terms in the Federal rule.

First, the definition for the term "withholding of medically indicated treatment" from a disabled infant is only partially restated and what is presented adds an incorrect treatment exception for disabled infants. The agency definition completely omits the Federal requirement that "appropriate nutrition, hydration, and medication" must always be given an infant with a disability. Furthermore, in defining exceptions to the normal requirement of maximal treatment, the procedures incorrectly state that treatment is not necessary when "(3) the treatment itself under such circumstances would be inhumane."[230]

This is a extremely significant misstatement of the third treatment exception of the Federal regulation. Under this exception, treatment is not mandated when "the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment under the circumstances would be inhumane."[231] In the Federal guidelines, inhumane treatments are those pursued although recognized as virtually futile with regard to the infant's survival. The Utah procedures separate the linkage between virtual futility and inhumaneness, and establish "inhumane treatment" as a separate and freestanding category. The inherent danger in such a construction is the necessary subjectivity involved in determination of what is "inhumane," an invitation to the use of quality of life considerations, which the CAA intends to foreclose in its formulation. (See Preface, NOTE F.)

In a September 24, 1988, letter, the agency responded to a preliminary draft of this report and attempted to address this criticism. However, it made no effort to explain or justify its misstatement of the legal standard of care. Instead, the agency's response concentrated on its exclusive authority to conduct the investigation:

> The quote received appears to indicate that the treating physician is the one who determines the "inhumane" treatment. As I view the entire section of procedures I interpret it to be referring to the treating physician not having that exclusive authority. That is, an investigation would be merited to gain consensus on the inability to ameliorate the life threatening conditions which results in the treatment being inhumane.[232]

Efforts to gain "consensus" on such a point violate the Federal rule, which requires that the humaneness of treatment can only be considered in conjunction after it has been determined that, even with treatment, there is only a remote possibility of the child's long term ability to survive.

The Utah procedures also inaccurately define the term "infant" to mean only an infant less than 1 year of age.[233] This 1-year limitation is clearly underinclusive enforcement of the CAA, and under it the agency fails to protect a large group of those required to be protected by Federal law. Commenting on relevant portions of a draft of the Commission report, the agency stated:

> The state has defined infant for purposes of these special procedures at under one year, however, our child neglect laws have mandated investigation of medical neglect for children from birth to age 18 since the initial legislation. I do not see the expressed conflict in Utah's definition and the regulation cited except that the cumbersome procedures are not in play after the child reaches one year.[234]

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[227] Telephone interview with Gary Jensen, Program Specialist, Division of Family Services (Aug. 2, 1988).

[228] *Id.*

[229] Letter from Gary Jensen, Program Specialist, Division of Family Services, to *Issues in Law and Medicine* (May 14, 1987).

[230] Utah Department of Social Services, Division of Family Services, Implementing Policy for Investigation of Allegations of Withholding of Medically Indicated Treatment To Disabled Infants with Life Threatening Conditions II. B.

[231] 45 C.F.R. § 1340.15(b)(2)(iii).

[232] Letter from Gary Jensen, Protective Service Specialist, Division of Family Services to T. Burke Balch, Office of the General Counsel, U.S. Commission on Civil Rights (Sept. 24, 1988).

[233] Utah Department of Social Services, Division of Family Services, Implementing Policy for Investigation of Allegations of Withholding of Medically Indicated Treatment To Disabled Infants with Life Threatening Conditions II. C.

[234] Letter from Gary Jensen, Protective Service Specialist, Division of Family Services to T. Burke Balch, Office of the

This reply evades the point that the medical treatment standards for disabled infants, the "cumbersome procedures" as the agency describes them, must be applied under Federal law to medical judgments concerning infants with disabilities beyond the first year. (See Preface, NOTE E.)

A further weakness in the Utah procedures is that there is no specification of the method for obtaining an independent third-party medical expert to conduct the examination, review the medical records, or otherwise assist the CPS worker in evaluating a report of medical neglect. Notwithstanding a reference that "DFS will provide outside medical evaluations as requested," there is no provision "for a court order for an independent medical examination" specified in State agency's procedures as required by the Federal regulations. (See Preface, NOTE D.) The medically untrained CPS worker appears to be alone in determining whether the health care facility is providing appropriate treatment. In fact, according to the policies, before making a determination as to the appropriateness of the treatment, the CPS worker is instructed to request the infant bioethics review committees to convene and review the case in instances where such a committee exists. In effect, the procedures appear to authorize the CPS worker to rely in some cases solely on the medical information received from the very hospital against which the complaint was lodged.

In short, the Utah procedures are completely contrary to Federal standards. The effectiveness of any investigation to discover if treatment is medically correct would be substantially improved were the agency to specify the use of an independent third-party medical consultant, selected with the benefit of advice from disability groups, to assist the CPS worker in all nonfrivolous cases. The procedures are out of compliance with Federal law when they present an underinclusive definition of those to be protected by the CAA, when they erroneously state that treatment need not be provided to a disabled infant if the treating physician considers it as "inhumane," and when they completely omit the legal requirement that infants with disabilities must always be given appropriate nutrition, hydration, and medication. The Utah procedures appear to allow the starvation of infants with disabilities if there is a "consensus" between the treating physician and the CPS agency that to do so would be "humane." Finally, Utah's characterization of the protective requirements of the CAA as "cumbersome procedures" bespeaks an agency more interested in evading than enforcing them.

VERMONT

The Vermont Division of Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that there had been no reports of medical neglect of infants with disabilities since the regulation went into effect.[235]

There is no record that disability rights groups were consulted in the formulation of State policy for a medical neglect cases. The agency reported that it consulted the Vermont chapter of the American Academy of Pediatrics and a representative from Vermont's only tertiary care hospital.[236]

Agency procedures were reviewed to determine consistency with Federal law. Enforcement mechanisms that are required by the Federal regulation to be specified in CPS procedures, such as the manner in which a CPS will obtain medical records and a court order for independent medical examination, are set forth. The definition of "withholding of medically indicated treatment," which establishes the standard of care, parallels that in the Federal regulation. However, no definition is given for the term "infant," which would establish the class of those protected by that standard of care. (See Preface, NOTE E.)

The agency procedures indicate that it alone makes the determination whether treatment of a child who is the subject of a complaint of medical neglect is in accord with the standards set forth in the CAA. To assist in this task, the procedures instruct the caseworker to "consult with the Pediatric Consultant for Infant Care Review (PC/ICR) to obtain the information and treatment recommendations necessary to the investigation and/or to develop a case plan." The procedures state that "[t]he investigation of the report remains open pending assurance that the PC/ICR consultation occurs

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General Counsel, U.S. Commission on Civil Rights (Sept. 24, 1988).

[235] Telephone interview with Maureen Thompson, Case Reviewer, Division of Family Services (Aug. 10, 1988).

[236] Telephone interview with Ellen Furnari, Department of Social and Rehabilitation Services, by *Issues in Law and Medicine* (June 16, 1987).

immediately and that the recommendations of the PC/ICR are implemented."[237]

Apart from the significant omission of a definition of class of children protected, on their face the Vermont procedures appear to comply with the CAA and their implementing regulation.

VIRGINIA

Virginia Child Protective Services (VCPS) in the Department of Social Services (DSS) is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

In developing its policies and procedures, DSS appears to have placed more emphasis on securing views of health care providers—those being regulated—than of groups representing people with disabilities—those being protected. Only a State agency was consulted for disability rights views; no private disability rights advocacy organizations were contacted, while the views of all the hospitals in the State were solicited.

> Our procedures were developed with the guidance of staff from the three major teaching hospitals in our state. Staff involved included physicians, nurses, administrators, clergy, ethics committee members and social workers. Additionally, the procedures, once drafted, were shared for comment with all of the hospitals in the state as well as all of the departments of social services who would be providing protective services. Our attorney provided legal review and the State Department for the Rights of the Disabled was consulted.[238]

Asked to comment on this criticism, DDS responded to the Commission that it solicited input from the Virginia Department for the Rights of the Disabled "as an advocacy office for all of the private disability rights advocacy organizations and individuals in the State." On the other hand, DDS maintained, "[v]iews of all hospitals were solicited since there was no central organization which represented their collective interests."[239]

The State's procedures were reviewed for compliance with the Federal regulation implementing the CAA. A definition of the term "withholding of medically indicated treatment" is present in the procedures and is consistent with the Federal regulation. Enforcement mechanisms required by the Federal regulation to be specified in CPS agency procedures, such as the manner in which a CPS agency will obtain medical records and court orders for independent medical evaluations, are also included. The procedures include no definition of the term "infant." However, a pamphlet published by the Commonwealth of Virginia for health care providers inaccurately defines an infant as "A child less than one year of age."[240] (See Preface, NOTE E.)

A further weakness is that the procedures do not specify the method for obtaining an independent third-party medical expert to assist the CPS worker in evaluating a report of medical neglect.

> SPECIAL CONSIDERATIONS/PROCEDURES FOR INVESTIGATING COMPLAINTS OF WITHHOLDING MEDICAL TREATMENT OF HANDICAPPED INFANTS
>
> . . . .
>
> f) if it appears that it is a situation of medical neglect, determine if immediate actions are necessary to maintain the child
>
> > *—the worker must assess the immediate situation utilizing any available information from the attending physician, other appropriate resources from the hospital and the complainant.* Access to the medical records and an independent medical exam of the infant are to be obtained with a court order when needed to assess the situation.[241]

Notwithstanding the reference to a court order for an independent medical examination, there is no mention of any method for obtaining an independent medical consultant to conduct the examination, review the medical records, or otherwise assist the CPS worker. Asked to comment upon this, the Virginia Department of Social Services responded that "the procedures do not include specific instructions on how to obtain medical consultation because this is a function of the state office."[242] It further stated:

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[237] Department of Social and Rehabilitation Services Policy Manual, pt. IV–E–16a.

[238] Letter from Janine Tondrowski, Program Specialist, Child Protective Services, to *Issues in Law and Medicine* (June 16, 1987).

[239] Letter from D. Ray Sirry, Director, Division of Service Programs, Department of Social Services, Commonwealth of Virginia, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 6, 1988).

[240] Virginia Department of Social Services Policies and Procedures, app. II, vol. VII, sec. III, ch. A, at 63. In commenting upon this, VCPS advised the Commission that it plans to revise the definition of infant contained in its pamphlet to include the definition specified in the Federal regulations. Letter from Janine Tondrowski, Program Specialist, Child Protective Services, to *Issues in Law and Medicine* (June 16, 1987).

[241] Virginia Department of Social Services Policies and Procedures, app. II, vol. VII, sec. III, ch. A, at 63, (emphasis added).

> Contacts were made and developed across the state to enable this consultation to take place when necessary. In the event of a complaint, the local department receiving the complaint is to contact the CPS Hotline. This contact initiates involvement of the state level policy specialist who would coordinate any needed consultation. Because of the geography of the Commonwealth, it was determined impractical to choose one medical consultant. Additionally, because of the adverse reaction to the initial regulations set out by the Federal government, no one physician was willing to accept such a responsibility. However, a number of specialists in neonatal medicine did agree to serve in a consulting capacity on a case-by-case basis should the need arise.

The agency reported in its letter to the Commission of October 6, 1988, that to date it had not received any complaints requiring investigation under its regulations. In addition, the agency had previously reported, in June 1987, that there had been no reports of disabled infants having been denied medical treatment.[243]

In some respects the procedures in effect in Virginia are in substantial compliance with the CAA. However, the effectiveness of any investigation to discover if treatment is medically correct would be substantially improved were the agency to specify in its procedures the use of an independent third-party medical consultant, selected with the benefit of advice from disability groups, to assist the CPS worker in all nonfrivolous cases. In addition, the definition of "infant" in the Federal regulations should be added to the Virginia procedures.

WASHINGTON

In Washington, the Division of Children and Family Services in the Department of Social and Health Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that it was aware of three reports of medical neglect of infants with disabilities since 1985, but it could not report a definite figure because a separate reporting category does not exist for these cases. "In each instance, the hospital reported to CPS seeking court intervention to permit continued treatment. The courts intervened and all three children are surviving."[244]

In a followup inquiry by Commission staff, the agency stated that an additional case had been reported. The staff person stated that all but one of the reports in the past 3 years had occurred when a doctor wished to provide treatment, but the parents refused to consent.[245]

To develop procedures for implementation of the CAA, the agency reported that it convened a Baby Doe Advisory Committee composed of practicing pediatricians, health care providers, representatives of the Washington State Hospital Association, the Washington Chapter of the American Academy of Pediatrics, the Washington State Medical Association, the Developmental Disabilities Planning Council, and numerous State agencies.[246]

These procedures were reviewed for consistency with the Federal standards. They set forth an enforcement mechanism to obtain medical records from the hospital. However, the State policy fails to specify how a "a court order for an independent medical examination of the infant" will be obtained by the agency, as required by the Federal regulation. (See Preface, NOTE D.)

A further weakness of the Washington procedures is the complete absence of definition of terms used in the Federal rule. Although the agency uses the phrase "withholding of medically indicated treatment" when it instructs CPS staff to pursue a dependency action to prevent such a withholding, it merely states "[s]uch treatment is not limited to the providing of appropriate nutrition, hydration and medication regardless of the infant's condition or prognosis."[247]

This clause is hardly instructive to the person given the duty to enforce the law. (See Preface, NOTE F.) In addition, the term "infant" is not defined in the procedures. (See Preface, NOTE C.)

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[242] Letter from D. Ray Sirry, Director, Division of Service Program, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 6, 1988).

[243] Letter from Janine Tondrowski, Program Specialist, Child Protective Services, to *Issues in Law and Medicine* (June 16, 1987).

[244] Letter from Richard Winters, Program Manager, Division of Children and Family Services, to *Issues in Law and Medicine* (Mar. 31, 1987).

[245] Telephone interview with Richard Winters, Program Manager, Division of Children and Family Services, by Commission staff (Aug. 1, 1988).

[246] Letter from Richard Winters, Program Manager, Division of Children and Family Services, to *Issues in Law and Medicine* (Mar. 31, 1987).

[247] Division of Family and Children's Services Manual, ch. 26.33(F)(7).

Preface, NOTES A and B.) In instances where there exists an infant care review committee at a hospital, the procedures eliminate the federally required CPS duty to determine if there is a withholding of medical treatment:

> PROCEDURES
>
> The format for investigating a referral in these hospitals is as follows:
>
> 1. Contact will be initiated with the designated representative or the hospital. After contact has been made the worker will: present the allegations contained in the referral; and request a review of the treatment being provided. (The review should be conducted by a hospital group such as an ICRC, bioethics committee, etc. or an ad hoc committee convened to review cases of this nature.)
>
> The worker should make him/herself available to participate in the review process. *By participation it is not meant that the worker is expected to or should attempt to pass judgment on the medical care provided.* Participation by the worker in the review provides an opportunity for discussion of the Department's concerns and can provide the worker with necessary information should further action be required.
>
> 2. If the review process indicates that the infant is being provided appropriate medical care, then the referral will be considered unsubstantiated and no further action taken.
>
> Appropriate medical care means that the review process has considered the infant's condition in regard to the need for nutrition, hydration, medication or other procedures which may be appropriate to ameliorate or correct the life-threatening condition.[254]

In those situations in which there is no ICRC, the procedures abdicate the question of determining medical neglect to the hospital contact person. Upon receipt of a report of medical neglect of a disabled infant, the procedures provide that the CPS worker must contact the "hospital liaison" and that "[i]f the hospital liaison determines that the infant in question is a patient and is being provided with the recommended treatment, then no further action will be taken and the report considered unsubstantiated."[255] This procedure disposes of the report of medical neglect even more summarily than the procedure incorporating an ICRC.

Underlying this CPS system's abdication of its responsibility is a great confidence in the medical providers who are the typical subjects of reports of medical neglect of children with disabilities. The West Virginia procedures state:

> *Commentary*
>
> The Department believes that medical personnel treating disabled infants are committed to providing appropriate care. The Department also realizes that the treatment of such infants is a delicate, difficult and demanding task for medical personnel. Our responsibility is to work with these medical personnel as necessary to insure that proper care is and continues to be provided.[256]

The West Virginia procedures are responsive only to the situation where parents do not wish to provide treatment. They do not at all contemplate the review of a medical provider's decision to withhold treatment when there may be an opportunity for life—a fundamental provision of the CAA. The flaw in this policy, notwithstanding the instruction to the CPS worker to "request an independent medical examination when necessary," is the fact that there is nothing in this procedure that indicates that there is an independent third-party medical examiner to assist the CPS.

In response to the criticism made in the report, the agency attempted to minimize the language of the policy by simply stating: "The Department directed its field staff to seek the advice of hospital personnel in deciding whether proper care was being provided. Whatever decision is reached by field staff is subject to State Office review before a final determination is made."[257] Notwithstanding this assurance, the policy remains in effect.

The agency's letter of comment evinced a less than enthusiastic commitment to the special need of children with disabilities for protection from discriminatory denial of life-saving medical treatment. The agency's Commissioner wrote:

> I trust that your report will place the issue of the protection of handicapped children with life threatening conditions from medical neglect in its proper perspective. This is an extremely sensitive issue as well as a controver-

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[254] West Virginia Department of Human Services, Memorandum from Rozella Archer, Director, Services to Families and Children, to Area Administrators, Social Service Coordinators [and] Child Protective Services Supervisors, Child Protective Services Policy pt. 3 (Aug. 28, 1986) (emphasis added).

[255] *Id.*, pt. 2.

[256] *Id.*, pt. 1.

[257] Letter from Regina S. Lipscomb, Commissioner, West Virginia Department of Human Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 6, 1988).

sial one. The number of cases comprise a tiny segment of the CPS population and should not be singled out for special treatment to the detriment of other children.[258]

In light of its deference to the hospitals that would be the subject of denial of treatment reports and its failure to promulgate adequate written procedures, West Virginia is fundamentally out of compliance with the CAA and its implementing regulation.

WISCONSIN

In Wisconsin, the Bureau for Children, Youth and Families of the Division of Community Services in the Department for Health and Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency stated that there had been no reports of medical neglect reported to the agency.[259] In a followup inquiry conducted by the Commission, the agency confirmed that there had been no reports in the State.[260]

The agency produced *Guidelines in Handling a Report of Possible Medical Neglect of a Disabled Infant* to implement a response system to reports of withholding of medically indicated treatment. In a policy memorandum dated August 4, 1988, the agency stated: "These guidelines were developed over the last nine months with the participation of a 30-person multidisciplinary informal advisory group (The Baby Doe Forum), Child Protective Services (CPS) Work Group and by an extensive internal review that included Department of Health and Social Services staff, developmental disabilities advocates, and legal counsel."[261]

The Wisconsin guidelines were reviewed for compliance with the Federal regulation implementing the CAA. They appear to be a comprehensive manual for a professional investigation of a report of medical neglect of an infant with disabilities. The manual offers step-by-step investigation directions and has appendices that instruct the CPS on information-gathering needs and the process of coming to a conclusion whether treatment is "medically indicated."

Definitions presented in the guidelines manual conform to the Federal regulation. The enforcement mechanisms that are required by the Federal regulation to be specified in the agency's procedures, such as the manner in which CPS will obtain medical records and court orders for independent medical evaluations, are set forth. The guidelines also provide for an independent medical consultant to be available to provide assistance to the CPS worker.

The Wisconsin procedures appear to comply with the Federal regulation implementing the CAA.

WYOMING

In Wyoming, the Children and Family Services Unit in the Division of Public Assistance and Social Services of the Department of Health and Social Services is the State agency responsible for enforcement of the Child Abuse Amendments of 1984 (CAA).

The agency reported that it had conducted one case investigation since the regulations went into effect.[262]

Regarding formation of its procedures, the agency reported that:

> In developing our materials [for investigations under the CAA] we cooperated with the Colorado State Department of Social Services and held joint training sessions. We also relied greatly on material prepared by the American Bar Association in their model procedures, and referenced the journals published by the National Legal Center for the Medically Dependent and Disabled.[263]

There was no indication, however, whether disability rights groups were consulted.

The procedures were reviewed for compliance with the Federal regulation that implements the CAA. The definitions of terms correctly reflect the Federal standards. In accord with the Federal regulation, the procedures specify how the department will obtain access to medical records and how it will obtain court orders for independent medical examinations and treatment. In addition, agency procedures present a detailed method for investigation by an independent medical consultant to conduct an examination, review the medical records, or otherwise assist the CPS worker. The agency reported that the medical consultants will be American Academy of Pediatrics board-certified neonatologists who had expressed concern about treatment of infants with disabilities issues. It stated that no consultant will investigate in the region where he or she practices.[264] The procedures state that "[a] decision to seek informal resolution, court ordered treatment or additional information, refer to case [sic] involving an infant death, or to close an unfounded case, shall be made by the CPS specialist in consultation with the CPS medical consultant and SD-PASS consultant."[265]

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[258] *Id.*

[259] Telephone interview with Michael Becker, Division of Community Services, by *Issues in Law and Medicine* (June 24, 1987).

[260] Telephone interview with Mary Dibble, Child Abuse and Neglect Specialist (Aug. 2, 1988).

[261] State of Wisconsin, Department of Health and Social Services, Division of Community Services, Memo Series DCS-88-66, Aug. 4, 1988.

[262] Telephone interview with Paul Blatt, Program Manager, Children and Family Services Unit (July 20, 1988).

[263] Letter from John Steinberg, Children and Family Services Unit, to *Issues in Law and Medicine* (Mar. 30, 1987).

On their face, the Wyoming procedures appear to comply with the CAA and their implementing regulation.

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[265] Children and Family Services Manual, vol. VI, pt. VI(A).

AFFECTED CPS AGENCY COMMENT PROCESS

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
ALABAMA	9/14/88	Alabama claimed that it is proper for an ICRC to decide if treatment is correct: "If a duly authorized ICRC decides that treatment should be withheld, there is no difference in medical opinion which would support court petition." With regard to the definition of infant, the State argued that because Alabama law provides that a child is anyone under the age of 18, the department would always investigate a report of medical neglect of any child regardless of age. And with regard to the report citing the agency for failure to include in its policy a provision for access to medical records, the agency wrote: "There is no provision in the federal regulations requiring that the State Plan or procedures outline in writing a procedure for obtaining medical records."	12/28/88	By letter of 1/5/89, the agency stated that: "Alabama will revise its regulations to state that a court order shall be obtained to obtain access to medical records . . . . Alabama will further clarify its written procedures to provide that a court order shall be obtained where examination of the infant is denied by the hospital . . . . Alabama will revise its written procedures to clarify that the medical neglect procedures apply to children past one year of age." With regard to the agency's reliance on a ICRC, the agency stated that: "Alabama's procedures have been approved by the federal Department of Health and Human Services. . . In any case, duly constituted ICRCs are rare in Alabama."
ALASKA	9/14/88	By letter of 10/12/88 the agency wrote: "The report names Alaska among the states that 'explicitly abdicate to internal hospital infant care review committees or hospital staffs the authority to decide whether illegal denial of treatment is received by the state agencies.' The Division of Family and Youth Services has promulgated no such policies and procedures and I am advised by the Office of the Attorney General that no other Alaska State agency has done so."	12/28/88	None.
ARIZONA	9/14/88	The agency disagreed with the report citing the agency for abdicating to ICRCs the question whether an illegal denial of medical treatment is taking place: "Infant Care Review Committees are always part of the investigation. This not an abdication to the ICRC, but rather inclusion of a major source of information." The agency denied that its reformulation of the treatment standard was inconsistent with the Federal rule: "This definition is in compliance with the Arizona statute and federal regulations . . . ."	12/28/88	By letter of January 23, 1989, the State asserted that it is neither the policy nor practice of the agency to consider the quality of life of an infant who is under an existing disability. Nevertheless, the State informed this office that it will suggest the following revision: "In any investigation under this Section the infant's current 'quality of life' due to an existing handicap or disability shall not be considered in determining whether Child Protective Services has sufficient grounds for action." In addition, the State asserted that CAA protection is limited to children less than 1 year of age because this is the scope of protection enumerated in the

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
ARIZONA (cont.)				statute and that the regulation merely suggests protection "to other classes." Nonetheless, the State informed this office that it will suggest the following revision: "In addition to applying to infants less than one year of age, the standards and procedures set forth in this article should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long term disability." The agency also assured the Commission that investigations by CPS would not cease merely because the parents and medical providers agree to withhold treatment. Nonetheless, the State informed this office that it will suggest the following revision: "In situations where the medical personnel and the child's parents or guardians are in agreement to withhold medical treatment for the infant, a dependency petition shall be filed, after decisionmaking process including the Child Protective Services supervisor and advice and counsel from an Assistant Attorney General, if Child Protective Services' independent evaluation shows that such medical care is being wrongfully withheld under applicable state and/or federal rules and regulations."
ARKANSAS	9/14/88	By letter of 10/10/88, the agency stated: "In our opinion Arkansas does meet the eligibility requirements of Public Law 93-247." The agency enclosed a packet of documents to demonstrate compliance. However, review of the documents found no specified manner in which the agency will obtain access to medical records or an independent medical examination, contrary to the requirements of the Federal regulation.	12/28/88	The agency sent a duplicate of its October submission and wrote: "We believe the enclosed information covers the issues you raised and is self-explanatory."
COLORADO	9/14/88	Colorado did not respond directly to the criticism that its policy did not show the method to be used to obtain an independent medical examination. Instead, the agency wrote: "Colorado county departments of social services do have the ability to obtain court-ordered independent medical examinations. Please find enclosed a copy of an Opinion of Colorado's Attorney General dated September 23, 1986 which addresses this issue. This Opinion was distributed to all county departments of social services and all hospitals as well as all other interested parties."	12/28/88	With regard to the fact that the agency has not made explicit in its procedures the method to be used to obtain an independent medical examination, the agency submitted revised procedures which showed that such a procedure exists. The report was revised accordingly. With regard to the absence of a specified medical consultant to assist the CPS, the agency wrote: "In this state supervised county administered system, the counties would make their own arrangements for independent medical examinations."

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
CONN.	9/14/88	Connecticut did not address the fact that its policy lacks written procedures for access to medical records and court orders for independent medical examinations. Instead, the agency cited State statutes which gave it legal authority to investigate.	12/28/88	Connecticut wrote: "We have taken steps to assure that our procedures are specific in regard to the manner in which the Department can obtain medical records or a court order for an independent medical examination."
DELAWARE	9/14/88	None.	12/28/88	With regard to the definition of infant, Delaware wrote: "[A]s noted, the Division procedures do not currently define the term 'infant'. A supplemental memorandum to the procedures has been issued to correct this." With regard to the report citing the agency for allowing hospital staff to initially determine if there is medical neglect, the agency claimed that it merely obtains initial information from the hospital staff. The agency did not directly respond to the report's observation that a conflict of interest exists when a hospital approves the independent medical reviewer. The agency claimed that "in a state the size of Delaware, it would be difficult, if not impossible, to locate a physician who did not in some way have an affiliation with the hospital or treating physician so as to avoid the impression of a conflict."
D. C.	No.	—	12/28/88	None.
FLORIDA	9/14/88	With regard to the report citing Florida for abdicating authority to an ICRC, the agency claimed "Health and Rehabilitative Services Pamphlet 175-1 dated July 1, 1988, specifically requires that CPS staff respond to reports of known or suspected abuse or neglect immediately or within 24 hours. State law mandates that health care personnel report these situations to the protective agency."	12/28/88	Florida wrote: "While we felt that we have been in compliance with federal guidelines it is clear that we need to readdress the issue based on your evaluation. Steps will be taken immediately to do this.
GEORGIA	9/14/88	None.	12/28/88	None.
HAWAII	9/14/88	With regard to the absence of a provision in agency policy to obtain a court order for an independent medical examination, the agency cited a State statute which "provides the basis upon which child protective services social workers may seek court intervention." Hawaii also defended a provision in its policy which abdicates authority to a hospital ICRC. Hawaii claimed: "Section 1100.9.2 states in	12/28/88	None.

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
HAWAII (cont.)		effect that further investigation may not be required if inquiry by child protective services staff, upon receiving a report of alleged medical neglect, finds that a second opinion concurs with the opinion of the treating physician." The agency also showed in its response that it had a method to obtain medical records and that the cite in the report was incorrect. The report was revised accordingly.		
IDAHO	No.	---	12/28/88	Idaho stressed that it is in full compliance with all Federal requirements. The agency also supplied the commission with the names of the organizations which contributed to the development of the agency procedures for the investigation of a report of medical neglect: "In our formulation stage of preparing draft policy and procedures on this topic, a committee was convened to draft proposed materials. This committee included the Chief of the Bureau of Developmental Disabilities of the Department of Health and Welfare. He received input from appropriate groups to include the Downs Syndrome Parents Support Groups, Coalition of Advocates for the Disabled, and other parents support groups for children with various disabilities." This information was included in the report.
ILLINOIS	No.	---	12/28/88	Illinois wrote: "The Department of Children and Family Services is the responsible agent for making the determination whether treatment is legally required under the 'medically indicated' definition set forth in the Child Abuse Amendments. In such role DCFS represents the interests of disabled infants and determines circumstances in which the power of the state must be invoked to protect infants and then take appropriate follow-up actions."
IOWA	9/14/88	With regard to the definition of infant, Iowa wrote: "I have attached proposed changes to the Iowa Administrative Code which we believe will bring us into compliance with CFR 1340.15. We have replaced the term 'infant' with 'child' as it is our belief that the regulation should apply to all children not just infants."	12/28/88	Iowa did not directly respond to the reports finding its agency lacked a policy seeking a court order for an independent medical examination as required by Federal regulation. Instead, the agency cited State statutes which gave the agency legal authority to investigate.

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
KANSAS	9/14/88	Kansas wrote: "If your Commission were to publish the report as presented to us it would not accurately reflect the policies and procedures in Kansas." Enclosed were the policies that the report had cited as absent and the report was revised accordingly. The agency stated: "We regret that we were not aware of the focus of your report nor that our statutes and administrative regulations would have been useful to you in addition to the policies requested."	12/28/88	The agency wrote: "Kansas has no comment."
KENTUCKY	9/14/88	Kentucky wrote "we appreciate the opportunity to respond to these areas in your report which reflect on medical discrimination against handicapped infants. As stated, we do take exception to your report in that regard and have cited Kentucky Revised Statutes and Departmental Policy in reaching our conclusions . . . ." Enclosed were policies that the report had cited as absent. The report was revised accordingly.	12/28/88	None.
LOUISIANA	No.	—	12/28/88	None.
MAINE	9/14/88	In response to the report excerpts citing the agency for allowing ICRC's to determine if treatment met CAA standards, the agency wrote: "The material related to medical treatment clearly gives the decision making about whether a case meets the 'Baby Doe' criteria to the Department not a hospital." With regard to the definition of "infant", the agency conceded that "infant" is not defined but claimed that investigations would take place if the definition under medical treatment standard is met. With regard to the report citing the agency for noncompliance with Federal regulations pertaining to independent medical exams and access to medical records, the agency submitted policies which showed that both were present. The report was revised accordingly.	12/28/88	The agency wrote: "I believe your conclusion is that Maine is in compliance other than not having an acceptable definition of infant. If this is indeed your conclusion, then I would concur."
MARYLAND	9/14/88	With regard to the lack of a CAA definition of infant, Maryland claimed: "Protective Services are provided to 'any individual under the age of 18 years,' when there is a report of medical neglect of a child with a life-threatening condition."	12/28/88	None.
MASS.	No.	—	12/28/88	None.

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
MICHIGAN	9/14/88	Michigan focused on parental autonomy in the treatment decision as the reason it did not investigate reports that a hospital is withholding treatment illegally: "Based on the preceding discussion that parents are the decision makers concerning the care and treatment for their disabled infant, CPS involvement is appropriate when parents are alleged to be neglecting their infant's care. An entity which is not the decision maker or responsible for the child's care is not appropriate for CPS involvement."	12/28/88	None.
MINNESOTA	9/14/88	Minnesota claimed that its policy's definition of infant was consistent with the Federal regulation: "Consistent with with 45 C.F.R. section 1340.15(b)(3)(i)(1987) Minnesota Rule on Child Protective Services and policy guidelines define infant less than one year of age."	12/28/88	The agency wrote: "We respectfully disagree with the conclusion that Minnesota's definition of the protected class is underinclusive. While the term infant is defined as less than one year of age, it is clear that the definition of infant medical neglect includes but is not limited to those children less than twelve months of age, which in essence more readily addresses the population of children protected by this section."
MISS	9/14/88	None.	12/28/88	Mississippi wrote: "[W]e are reviewing your report along with our policies and procedures. We are also reviewing your report with our Regional Office of Health and Human Services who has found our policy to be in compliance."
MISSOURI	9/14/88	Missouri submitted a policy that showed it had in fact an explicit procedure to be used to obtain an independent medical examination. The report was revised accordingly. With regard to the definition of infant, Missouri claimed that "[t]he regulation defines 'infant' as an infant less than one year of age. It then clarifies that treatment should not be changed or discontinued when the infant reaches one year or older. All children, including sub-population known as 'Baby Doe,' are protected through our child abuse and neglect statute . . . . Therefore, once an infant reaches one year of age our statute still requires appropriate treatment to be provided."	12/28/88	Missouri submitted a policy with a current medical treatment standard. The report was revised accordingly. Concerning the agency's deference to ICRCs, Missouri wrote: "The Division is very aware of its responsibility under federal and state statute to assure that a comprehensive investigation is conducted and to make the final determination relating to a child abuse/neglect report. Again, in order to make that commitment clear to the Commission I have attached a revision to Procedure A-7 of the Investigation Handbook." With regard to the definition of infant, the agency wrote: "I have attached a a revision to our definition of infant which will immediately be inserted in the Investigation Handbook."

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
MONTANA	9/14/88	Montana did not directly respond to the fact that it is not explicit in the methods it will obtain independent medical examination and access to medical records as required by Federal regulation. Instead, the agency emphasized that it had statutory authority to do so if need be. The agency explained that "the department does not restate provisions of state law in its policy manual since to do so would be duplicative and would result in an unnecessarily voluminous policy manual." Concerning the absence of a defined standard of care and the lack of a definition of the class protected, the agency cited State statutes which defined both. The agency claimed that "[i]t is necessary to read the statutes and the policy together to gain an accurate understanding of Montana's program for reports of medical neglect."	12/28/88	Montana submitted a current policy which showed that procedures are in effect to obtain medical records and an independent medical examination. The report was revised accordingly.
NEBRASKA	9/14/88	Nebraska submitted policies that showed that it had in fact explicit procedures to obtain access to medical records and a court order for an independent medical examination.	12/28/88	None.
NEVADA	9/14/88	None.	12/28/88	None.
NEW HAMPSHIRE	No.	---	12/28/88	The agency disavowed statements made by its Medical Neglect Investigator concerning the futility of treating a disabled child. The Director stated that the individual did not speak with authority and was no longer with the agency. The agency wrote that "[t]he Division does not decide to conduct an investigation based on the quality of a child's life and it certainly will not decide to obtain medical treatment based on the quality of a child's life." The report was revised accordingly.
NEW JERSEY	9/14/88	New Jersey claimed that it was unnecessary to print the CAA treatment standard and the class the standard protects in its policies because pre-CAA State statutes served the same purpose: "It is our contention that the present New Jersey statutes meet the definitions of the standards of treatment set forth in the Child Abuse Amendments of 1984, and that N.J.S.A. 9:6-8.9 and N.J.S.A. 9:6-8.21 adequately define the terms 'child' to include infants and children over one year and 'withholding of medically indicated treatment'. The policy on the other hand, sets forth the philosophical orientation as well as a process by which to conduct these investigations in the least intrusive manner to the family, the physician, and the health facility."	12/28/88	None.

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
NEW MEXICO	9/14/88	None.	12/28/88	New Mexico wrote that it would remove from its policy that provision which instructs CPS staff to list reports of medical neglect as "unsubstantiated" when both parents and physician agree to withhold treatment. The agency also submitted policies that showed it had the ability to obtain medical records, independent medical examinations, defined the standard of care, and defined the class protected. The report was revised accordingly.
NEW YORK	9/14/88	New York wrote: "I would say that we do not expressly define infant and withholding of medically indicated treatment. I would add though existing New York law is sufficiently clear as to who is afforded protection and under what circumstances protection is needed."	12/28/88	With regard to the fact that there are no express policies to obtain access to records and independent medical examination as required by Federal regulation, New York pointed to informal procedure and statutes that could be availed: "Obtaining a child's medical records is a well established procedure. Family Court law in New York State contains written procedures for obtaining an independent medical examination when medical neglect is suspected."
NORTH CAROLINA	No.	---	12/28/88	None.
NORTH DAKOTA	9/14/88	None.	12/28/88	North Dakota wrote that it would revise its policy to include an expanded definition of infant.
OHIO	9/14/88	Ohio cited an administrative rules definition of "child" as the reasonable facsimile for the CAA's definition of "infant."	12/28/88	None.

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
OKLAHOMA	No.	---	12/28/88	By letter of January 23, 1988, the agency explained why it did not develop specific procedures under the CAA: "[L]ongstanding policy and state law authorized a full panoply of legal remedies, access to children's medical records, and medical examination of children whenever abuse or neglect of any kind was at issue. . . . Additionally, recently proposed revisions (developed from DHS's standard ongoing review of policy) incorporates all of the criteria and purposes of the federal regulation. . . . These provisions simply consolidate existing memos in one section, and adoption by the Director is anticipated very soon."
OREGON	9/14/88	With regard to agency policy language that allows overruling a parental decision of nontreatment only when an ICRC finds treatment is medically indicated, Oregon claimed: "The Medical Neglect Investigator determines the course of action to be taken including whether or not there should be court involvement. Information is obtained from the attending physician, the hospital review committee, the consulting neonatologist and other appropriate medical professionals, but the Medical Neglect Investigator is the one responsible for deciding if legally required treatment is being withheld."	12/28/88	Concerning policy language which allows an inappropriate amount of authority to the ICRC, Oregon claimed: "Nowhere in these sections does it state that the Hospital Review Committee or a physician have the authority or responsibility to determine whether or not there has been an illegal denial of medical treatment."
RHODE ISLAND	No.	---	12/28/88	With regard to policy language that limits CPS intervention to parents who refuse consent to treatment, Rhode Island claimed: "I wish to advise you very clearly that we would initiate an investigation if an allegation is received that a physician with or without the consent of the parent is denying legally required treatment."
SOUTH CAROLINA	No.	---	12/28/88	None.
SOUTH DAKOTA	No.	---	12/28/88	With regard to ICRC involvement, South Dakota wrote that "the procedure by which Child Protection Services relies on the results of the medical consultant's discussion with the ICRC representative will be reviewed by the South Dakota Department of Social Services." Concerning the definition of infant, the State wrote that its "procedures will be updated to define infant as defined by HHS regulations."

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
TENNESSEE	9/14/88	Tennessee showed that it had policies which enabled it to obtain independent medical examinations and an infant's medical records. The report was revised accordingly. With regard to the absence of the CAA standard of care in its policy, Tennessee wrote: "Within CPS policy severe abuse is defined to include a life-threatening condition. This CPS policy allows us to intervene on behalf of handicapped infants." Concerning a definition of infant, the State wrote: "Within policy and practice we investigate and provide services to all children under the age of 18 who are at risk of abuse or neglect. Handicapped infants are included within this mandate."	12/28/88	None.
TEXAS	9/14/88	Concerning the definition of infant, Texas wrote: "It is correct that Texas does not define the term "infant" in either the Texas Family Code or the Texas Department of Human Services Child Protective Services Handbook."	12/28/88	The State claimed: "We disagree that not defining infant is a deficiency. We apply the regulations to all children (under age 18) who meet the criteria in the regulations, including infants."
UTAH	9/14/88	Utah made no effort to justify or explain policy language which misstates the legal standard of care. Instead, the agency explained its exclusive authority to determine medical neglect, an issue never brought out by the report: "The quote received appears to indicate that the treating physician is the one who determines the 'inhumane' treatment. As I view the entire section of procedures I interpret it to be referring to the treating physician not having that exclusive authority." Concerning the definition of infant, the State wrote: "The state has defined infant for purposes of these special procedures at under one year, however, our child neglect laws have mandated investigation of medical neglect for children from birth to age 18 since the initial legislation. I do not see the expressed conflict in Utah's definition and the regulation cited except that the cumbersome procedures are not in play after the child reaches one year."	12/28/88	None.
VERMONT	9/14/88	None.	12/28/88	With regard to a definition of infant, Vermont wrote that "we will be adding immediately the definition of 'infant' to our regulations using the HHS definition in the Federal Register."
VIRGINIA	9/14/88	Virginia advised that it would revise its definition of infant to reflect the HHS regulation.	12/28/88	Virginia wrote: "The revised draft accurately reflects our comments as submitted to you in an October 6, 1988, letter."

STATE	RELEVANT EXCERPTS SENT TO CPS	CPS RESPONSE AND REPORT REVISIONS	REVISED EXCERPTS SENT TO CPS	ADDITIONAL CPS RESPONSE
WASHINGTON	9/14/88	Washington did not directly address the substance of the report. Instead, the agency wrote: "I am concerned by the lack of coordination with Department of Health and Human Services, especially region offices and with this state. Information which is readily available through either of these sources would appropriately address some of the concerns highlighted in the report."	12/28/88	Washington claimed: "If you have concerns with the HHS interpretation of its own rule, then your challenge should be directed to that agency and not be directed at the states. Perhaps their further clarification would address your concerns."
WEST VIRGINIA	9/14/88	With regard to the lack of a definition of infant and the standard of care, West Virginia wrote: "It is our expectation, based upon experience, that any questions as to whether or not a child is neglected will be referred to our State Office for review and final decision." Concerning its deference to the hospital under investigation, the agency wrote: "The Department directed its field staff to seek the advice of hospital personnel in deciding whether proper care was being provided. Whatever decision is reached by field staff is subject to State Office review before a final determination is made."	12/28/88	None.
WISCONSIN	9/14/88	Wisconsin submitted current policy that contained those procedures that the report had previously cited as absent. The report was revised accordingly.	12/28/88	None.
WYOMING	No.	---	12/28/88	Wyoming wrote: "I have reviewed the excerpts from the draft report on Medical Discrimination Against Children with Disabilities. I am not aware of any errors in these materials."

ANALYSES OF CPS COMPLIANCE WITH THE CAA

STATE	CAA REQUIREMENT FOR INDEPENDENT MEDICAL EXAM?	CAA REQUIREMENT FOR ACCESS TO MEDICAL RECORDS?	CAA DEFINITION OF INFANT USED?	CAA TREATMENT STANDARD USED?	RETAINS FULL CAA RESPONSIBILITY FOR THE INVESTIGATION?
ALABAMA	Yes - but an opinion will be sought only when no ICRC exists at a hospital.	No - procedures contain no such provision.	No - protection limited to children less than 1 year of age.	Yes - standard is reprinted verbatim.	No - CPS allows ICRC to determine if treatment is consistent with the CAA and will not investigate if there is no dispute between the attending physician and the hospital ICRC. See app. C, Alabama, for details.
ALASKA	Yes - but an opinion will be sought only when no ICRC exists at a hospital.	Yes - but only when there is no ICRC.	No - protection limited to children less than 1 year of age.	Yes - standard is reprinted verbatim.	No - CPS directs all complaints to hospital review board for a determination whether a complaint is "valid."
ARIZONA	Yes.	Yes.	No - protection limited to children less than 1 year of age.	No - ambiguity permits "quality of life" factors to be considered. See app. C, Arizona, for details.	No - it appears that the agency will intervene only where disagreement exists between the hospital and the parents. See app. C, Arizona, for details.
ARKANSAS	No - procedures contain no such provision.	No - procedures contain no such provision.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	No - the hospital that is most frequently under investigation for medical neglect was permitted to write the rules of investigation and to name the "independent" medical reviewer.
COLORADO	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes - but agency evidently lacks independent medical consultants which could produce undue reliance on the ICRC. See app. C, Colorado.
CONNECTICUT	No - procedures contain no such provision.	No - procedures contain no such provision.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
DELAWARE	Yes.	Yes.	No - the protected class is not described.	Yes - standard is reprinted verbatim.	No - CPS allows the hospital "contact person" to determine if treatment is consistent with the CAA and the hospital pre-selects the independent medical reviewer.
DISTRICT OF COLUMBIA	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes - but the agency indicated that it regards the hospital's ICRC as the forum to resolve the cases. See app. C, District of Columbia.

STATE	CAA REQUIREMENT FOR INDEPENDENT MEDICAL EXAM?	CAA REQUIREMENT FOR ACCESS TO MEDICAL RECORDS?	CAA DEFINITION OF INFANT USED?	CAA TREATMENT STANDARD USED?	RETAINS FULL CAA RESPONSIBILITY FOR THE INVESTIGATION?
FLORIDA	No - procedures contain no such provision.	Yes - but only when there is no ICRC.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	No - CPS allows the "hospital liaison" and/or the ICRC to determine if treatment is consistent with the CAA.
GEORGIA	No - procedures contain no such provision.	No - procedures contain no such provision.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	No - CPS allows the hospital ICRC to determine if treatment is consistent with the CAA.
HAWAII	No - procedures contain no such provision.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	No - CPS will not investigate a report if any other medical opinion exists to support an attending physician's judgement about withholding treatment.
IDAHO	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
ILLINOIS	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
IOWA	Yes - but manner of obtaining court order is not mentioned.	Yes.	Yes - definition is reprinted verbatim.	No - standard of care is not described in the procedures.	Yes.
KANSAS	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
KENTUCKY	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
LOUISIANA	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
MAINE	Yes.	Yes.	No - the protected class is not described.	Yes - standard is reprinted verbatim.	No - a circular distributed to CPS staff recommends that CPS allow the ICRC to determine if treatment is consistent with the CAA. See app. C, Maine, for details.
MARYLAND	Yes.	Yes.	No - the protected class is not described.	Yes - standard is reprinted verbatim.	Yes.

STATE	CAA REQUIREMENT FOR INDEPENDENT MEDICAL EXAM?	CAA REQUIREMENT FOR ACCESS TO MEDICAL RECORDS?	CAA DEFINITION OF INFANT USED?	CAA TREATMENT STANDARD USED?	RETAINS FULL CAA RESPONSIBILITY FOR THE INVESTIGATION?
MASSACHUSETTS	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes - but agency evidently lacks independent medical consultants which could produce undue reliance on the ICRC. See app. C, Massachusetts, for details.
MICHIGAN	Yes - but an opinion will be sought only when no ICRC exists at a hospital.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	No - CPS will not respond to reports from parents that the hospital is not providing treatment for their child and will direct all complaints to hospital ICRC. See app. C, Michigan, for details.
MINNESOTA	Yes.	Yes.	No - protection limited to children less than 1 year of age.	Yes - standard is reprinted verbatim.	Yes.
MISSISSIPPI	No - procedures contain no such provision.	No - procedures contain no such provision.	No - the protected class is not described.	No - standard of care is not defined.	Yes - but the investigation procedures are ad hoc, incomplete and lack the input of independent medical consultants.
MISSOURI	Yes - but only if no parental consent or if ICRC disagrees with attending physician's treatment.	Yes.	Yes	Yes - standard is reprinted verbatim.	Yes - but the agency places undue reliance on the judgements of the hospital review committee. See app. C, Missouri, for details.
MONTANA	Yes.	Yes.	No - the protected class is not described.	No - standard of care is not described in the procedures.	Yes - but see app. C, Montana, for practice of "joint examination" of an infant between the AAP medical consultant and the attending physician.
NEBRASKA	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
NEVADA	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	No - CPS allows the hospital ICRC to determine if treatment is consistent with the CAA.
NEW HAMPSHIRE	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes - but the agency indicated that there would be no further investigation if an ICRC approved the treatment decision. See app. C, New Hampshire, for details.

STATE	CAA REQUIREMENT FOR INDEPENDENT MEDICAL EXAM?	CAA REQUIREMENT FOR ACCESS TO MEDICAL RECORDS?	CAA DEFINITION OF INFANT USED?	CAA TREATMENT STANDARD USED?	RETAINS FULL CAA RESPONSIBILITY FOR THE INVESTIGATION?
NEW JERSEY	Yes.	Yes.	No - protected class is not described.	No - standard of care is not described in the procedures.	Yes.
NEW MEXICO	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	No - CPS will not investigate if parents and a physician agree that treatments should be withheld.
NEW YORK	No specific procedures were established to respond to a medical neglect situation. Therefore, there are no provisions for independent medical examination or access to medical records. Neither the definition of infant nor the CAA standard of care are described. In addition, the agency indicated that there were no specific guidelines indicating who should be consulted if a medical neglect situation arises. See app. C, New York, for details.				
NORTH CAROLINA	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes - but CPS evidently has no independent medical expert and allows the hospital to be the primary resource for "consultation." See app. C, North Carolina, for details.
NORTH DAKOTA	Yes.	Yes.	No - protected class is not described.	Yes - standard is reprinted verbatim.	Yes.
OHIO	Yes.	Yes.	No - protection limited to children less than 1 year of age.	Yes - standard is reprinted verbatim.	Yes.
OKLAHOMA	No - procedures contain no such provision.	No - procedures contain no such provision.	No - protected class is not described.	No - standard of care is not described in the procedures.	No - CPS allows the hospital ICRC to determine if treatment is consistent with the CAA.
OREGON	Yes.	Yes.	No - protection limited to children less than 1 year of age.	Yes - standard is reprinted verbatim.	No - CPS terminates its investigation when a hospital ICRC determines that treatment is consistent with the CAA.
RHODE ISLAND	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
SOUTH CAROLINA	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.

STATE	CAA REQUIREMENT FOR INDEPENDENT MEDICAL EXAM?	CAA REQUIREMENT FOR ACCESS TO MEDICAL RECORDS?	CAA DEFINITION OF INFANT USED?	CAA TREATMENT STANDARD USED?	RETAINS FULL CAA RESPONSIBILITY FOR THE INVESTIGATION?
SOUTH DAKOTA	Yes.	Yes.	No - protected class is not described.	Yes - standard is reprinted verbatim.	Yes.
TENNESSEE	Yes.	Yes.	No - protected class is not described.	No - standard of care is not described in the procedures.	Yes.
TEXAS	Yes.	Yes.	No - protected class is not described.	Yes - standard is reprinted verbatim.	Yes - but the agency evidently lacks independent medical reviewers.
UTAH	No - procedures contain no provision for the court order.	Yes.	No - protection limited to children less than 1 year of age.	No - "inhumane treatment" provision misstates the standard. See app.B, Utah, for details.	Yes - but the agency lacks independent medical reviewers which could cause undue reliance on hospital ICRCs. See app. C, Utah, for details.
VERMONT	Yes.	Yes.	No - protected class is not described.	Yes - standard is reprinted verbatim.	Yes.
VIRGINIA	Yes.	Yes.	No - protected class is not described.	Yes - standard is reprinted verbatim.	Yes - but the agency lacks independent medical reviewers which could cause undue reliance on hospital ICRCs. See app. C, Vir., for details.
WASHINGTON	No - procedures contain no such provision.	Yes.	No - protected class is not described.	No - procedures do not define the standard of care.	No - CPS allows the hospital ICRC to determine whether treatment is consistent with the CAA.
WEST VIRGINIA	Yes.	Yes.	No - protected class is not described.	No - standard of care is not described in the procedures.	No - CPS allows the hospital ICRC to determine whether treatment is consistent with the CAA.
WISCONSIN	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.
WYOMING	Yes.	Yes.	Yes - definition is reprinted verbatim.	Yes - standard is reprinted verbatim.	Yes.

Appendix D

Verified Answers

State of Oklahoma
Department of Human Services
Sequoyah Memorial Office Building
P O Box 25352
Oklahoma City, Okla 73125

COMMISSION
FOR HUMAN SERVICES
Burns Hargis, Chairman

DIRECTOR
OF HUMAN SERVICES
Phil Watson

January 19, 1989

William J. Howard
General Counsel
U.S. Commission on Civil Rights
1121 Vermont Ave., N.W.
Washington, D.C. 20425

RE: Commission Report on
Handicapped Newborn

Dear Mr. Howard:

The State of Oklahoma has been and continues to be in substantial compliance with the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5101 et seq., Section 4(b)(2)(k) of the Child Abuse Ammendments of 1984, and its implementing regulation contained in 45 C.F.R. § 1340.15. The Department of Human Services, acting as the "properly constituted authority" within the state, has exerted a good faith and successful program to aggressively pursue and enforce federally mandated goals and objectives of the above referenced laws and regulatory guidelines.

The agency's former Director, Mr. Robert Fulton, initiated the state's efforts on January 2, 1985, in response to draft regulations implementing Pub. L. 98-457. (See copy of memorandum included as Attachment 1.) Subsequent to the publishing of new regulations in the Federal Register in April, 1985, this agency developed appropriate written notices for all hospital facilities in Oklahoma. The Commission's attention is directed to Attachment 2 which is a copy of the formal written notices to hospital administrators transmitted August 23, 1985.

The requirements of Section 1340.15 were fully complied with in the notice in discussing the obligations of facilities under the new rules. Mr. Michael Fogarty, Assistant Director of the agency's Medical Services Division, informed each facility of the strict requirements of the law. For example, he included the criteria of § 1340.15(2)(ii) demanding that each hospital designate a person responsible for reporting suspected medical neglect including the withholding of medically indicated treatment from disabled infants with life threatening conditions. Although the administrator was presumed to be the designee, the facility was required to report the name of the individual.

Within the agency, the Child Abuse Unit was authorized to "coordinate and consult" with designated hospital representatives in compliance with § 1340.15(2)(i). The name, address and telephone number of the supervisor (Ms. Ann Beam) was incorporated in the notice. Concomitantly, the facility was apprised of its obligation under federal law to "promptly" notify the Unit of any cases of suspected medical neglect (as required under subsection (2)(ii)). Indeed, the agency notice exceeds federal requirements by directing designees to utilize the 24 hr./7 day per week Child Abuse Hotline whenever the main office is closed.

The additional facility responsibility to update designee information annually was also noted as mandated under subsection (3) of the regulation. Furthermore, a form was provided for the facility to utilize initially and with subsequent updates. (A copy is included with Attachment 2 for your review.)

Notwithstanding any misunderstandings resulting from informal phone contacts between C.C.R. staff and Ms. Diana Stell, Oklahoma Department of Human Services written policy contains numerous sections which authorize and encourage action to protect infants and children from either abuse or neglect including medical neglect. Additionally, recently proposed revisions (developed from DHS's standard ongoing review of policy) incorporates all of the criteria and purposes of the federal regulation. (See copies of proposed revised policy dated December 12, 1988 marked Attachment 3.) These provisions simply consolidate existing memos in one section, and adoption by the Director is anticipated very soon.

It should be recognized, however, that longstanding policy and state law authorized a full panoply of legal remedies, access to children's medical records, and medical examination of children whenever abuse or neglect of any kind was at issue. For example, sections 620-624 discuss, in minute detail, procedures available to commence investigation of suspected abuse or neglect, initiation of legal proceedings through the appropriate district attorney or the agency's legal division, acquisition and protection of the medical records of children, coordination with various law enforcement officials, and insuring medical exams and treatment. Moreover, state law contained in 21 Okl. Stat. § 845 specifically authorizes legal action for protection of abused or neglected children. The requirement of "prompt notification" was codified previously in Section 846. These statutes, as well as the above written policy, pertain to any child from birth through eighteen (18) years of age.

As evidenced by the attached notices, the National Center on Child Abuse, D.H.H.S., has approved grants encompassing four consecutive fiscal years for Oklahoma's Child Abuse and Neglect (Disabled Infants)/ Infant Care Review Committee Project. (See copies designated Attachment

4). Considerable time, expense and effort was devoted to the application process as well as operation of the program. Suffice it to say that the State of Oklahoma and this agency considers the program and its purpose to be of major importance.

There have been four (4) cases which were reported as suspected medical neglect and withholding medical treatment. All four cases were investigated by the appropriate authority. Written reports with recommendations were provided to the district attorney for review. Each case was additionally reviewed by the Infant Care Review Committee at Children's Hospital of Oklahoma. However, DHS made the decision as to referral to the district attorney.

In three (3) of the reported cases, the district attorney filed petitions seeking an emergency order for consent to necessary medical treatment and/or placement of custody with Child Protective Services for the purpose of consenting to necessary medical treatment. In all three (3) cases, hearings were held before a judge. The Court granted the motions with treatment ultimately provided.

Of those three (3) cases, two (2) have since been dismissed and closed and the other remains open with the child a ward of the court. None of the children have died in these three (3) cases.

Records of the fourth case were not received in the state office (from the county DHS office) at the time of the informal phone contact with Ms. Stell in late July, 1988. The allegations contained in the Commission report are incorrect. Indeed, this agency is unable to determine the source of these unfounded allegations. If the Commission desires further verification, please inform this agency of the sources of the information, dates, names and other necessary data such as hospital, physicians/nurses involved, and case numbers.

In summary, this agency respectfully disagrees with the Commission's initial report findings. Despite the fact that the report was promulgated based upon incomplete and inaccurate information, this agency feels confident that the Commission will revise its findings accordingly, and consider the Oklahoma Department of Human Services in full compliance with all relevant federal laws, rules, regulations and guidelines.

It is the genuine hope of this agency that the Commission can devote its time and resources to other equally compelling and urgent civil rights matters affecting human dignity such as discrimination based upon race, ethnicity, and sex. These problems have proliferated dangerously in the past several years. This agency is equally committed to aggressively eliminating all vestiges of civil rights discrimination, and will endeavor to vigorously protect the personal rights and freedoms of our clients. Your interest and concern is appreciated, and we trust that this matter is resolved to your satisfaction.

With regard to future communications on this subject or other significant areas of concern, please direct written inquiries to the Office of General Counsel at the letterhead address. This will avoid future misunderstandings, delay and expense to all concerned.

Respectfully submitted,
Charles Lee Waters
General Counsel

John G. Fears
Assistant General Counsel

JGF:la

Enclosures

[Editor's Note: The attachments to this letter are available from the Office of General Counsel, U.S. Commission on Civil Rights, Washington, D.C. 20425. The attachments are:

1. Memorandum, Jan. 2, 1985, from Robert Fulton, on New Draft Federal Regulations on "Baby Doe" Legislation
2. Letter to Hospital Administrators, Aug. 23, 1985, on requirement to name individual to report medical neglect of disabled infants.
3. Rules on Reports of Abuse in Out-of-Home Care, 12/12/88
4. Grant award forms from National Center on Child Abuse for 1985-86, 1986-87, 1987-88, and 1988-89
5. Regulations on Child Abuse/Neglect/Intake/Legal Process issued 10-1-84, secs. 620-624.42
6. Regulations on Oklahoma Children's Memorial Hospital issued 7-15-79, secs. 670-675
7. Regulations on Division of Child Welfare issued 8-3-79, secs. 680-685.5
8. Regulations on Documentation of Service Delivery issued 6-15-79, secs. 690-697.2]

State of Oklahoma
Department of Human Services
Sequoyah Memorial Office Building
P.O.Box 25352
Oklahoma City, Okla. 73125

COMMISSION
FOR HUMAN SERVICES
Berna Hargis, Chairman

DIRECTOR
OF HUMAN SERVICES
Phil Watson

August 10, 1989

Reply to
the attention of:

Mr. Vincent Mulloy
Office of General Counsel
U.S. Commission on Civil Rights
1121 Vermont Ave., N.W.
Washington, D.C. 20425

RE: Request for Clarification of January 19, 1989
Correspondence from Department of Human Services
Office of General Counsel

Dear Mr. Mulloy,

I have personally reviewed detailed documentation relating to the four cases in which Oklahoma Youth Services personnel investigated alleged medical neglect. Additionally, I interviewed Ms. Diane Stell concerning any conversations she may have had with representatives of your office in 1988.

All four cases reported in my correspondence of January 19, 1989, were correctly recorded and verified, in each case, by treating physicians, the ICRC of the respective hospital, an independent physician not involved in the patient's care, Youth Services investigative personnel and their supervisors, district attorneys, judges in the counties in question, and of course, the State Office of DHS.

Ms. Stell presented the log with information of the referrals for my review. Although she was under the assumption that her phone conversations in 1988 were with federal HHS employees, she stated that it is possible that an employee of the Commission contacted her. However, she is adamant that the information she provided by phone was read directly from the log. Finally, the information I provided in January, 1989 corresponds to the original entries on the log. Indeed, Ms. Stell's statements to me yesterday are identical to statements she made to me in January.

The Commission's rough draft was, in fact, inaccurate. The only conceivable explanation is that the Commission's representative incorrectly recorded Ms. Stell's statements. Of course, one of the cases was not recorded on the log until after the telephone conversations with Ms. Stell. I reported that case, however, in my January

correspondence. In any event, it is highly questionable that the representative failed to request in writing similar verification from Ms. Stell in 1988 immediately following the phone conversations.

Because of applicable statutes, regulations and policy, no identifying information can be provided without written consent of the parties. Investigations indicated that the parents in those cases were refusing to consent to treatment protocols. All four cases were referred to the appropriate district attorney pursuant to state law and agency and hospital policies. In three of the cases, the district attorney sought and obtained court orders granting DHS custody for purposes of consenting to treatment. In those three cases DHS obtained the appropriate treatment, and all three children are alive although severely handicapped.

In the fourth case, the district attorney required further investigation and advice of medical experts. It was determined by an independent physician (who was ultimately in agreement with the treating physician and ICRC) that the infant's condition was inoperable. The infant had already undergone two extensive exploratory operations. The treating physician determined that there was no known cure or surgical procedure available. Separate inquiries by the independent physician and ICRC both determined that there were no known survivors in medical literature with the degree of dysfunction observed and documented in the infant. Further, death was imminent regardless of any treatment protocol that might be chosen. It was also evident that further surgical intervention would have resulted in a slower, painful, more agonizing death.

The district attorney, based upon the above investigative findings, declined to pursue legal action, civil or criminal, against the parents or physician. Although the anonymous complaint was initially made against the treating physician, the investigators, independent physicians, ICRC, and parents were unanimous in stating that the treating physician did not neglect or withhold treatment. To the contrary, the treating physician and parents each stated that the physician fully explained all treatment protocols, the diagnosis and prognosis, and advised them to seek a second opinion. The medical records and laboratory tests supported the opinion of the physician.

The parents refused to consent to additional surgical intervention. Their final stated decision and written consent was to make their infant as painfree and comfortable as possible. Pain medication was prescribed and administered. The physician also prescribed, and the hospital administered, nutrition and hydration intravenously. This case arose prior to current federal law but would clearly have met all of the three exceptions to mandatory treatment outlined in 45 C.F.R. § 1340.15.

REQUEST TO THE COMMISSION

The verified records of these four cases demonstrate conclusively that the Commission's rough draft was in error. Since publication of inaccurate data would be quite embarrasing to individual Commission members, the State of Oklahoma requests that the final report be corrected prior to printing. In addition, correspondence (with all attachments) including the responses to Mr. Howard dated January 19, 1989, and April 24, 1989, this response to Mr. Mulloy, and the Order granting defendants' Summary Judgment in *Johnson, et al v. Sullivan, et al* (a copy is attached hereto), should be attached in full to the final report. Finally, please forward a printed copy of the report to the undersigned with appropriate billing.

Because the State of Oklahoma and Department of Human Services are complying fully with the examplary provisions of the Child Abuse and Treatment Act, 42 U.S.C. § 5101 *et seq.*, Section 4(b)(2)(k) of the Child Abuse Amendment of 1984, and 45 C.F.R. § 1340.15, the General Counsel requests that any other alleged medical neglect, or allegations of failure to investigate properly medical neglect, known to the Commission, be forwarded to the undersigned. The Commission can be assured that immediate and appropriate investigation and action will be initiated by this office.

Please confirm in writing the receipt of this mailing (including attachments) mailed express this date.

Sincerely,

John G. Fears
Assistant General Counsel

JGF:la

cc: Governor Henry Bellmon

IN THE UNITED STATES DISTRICT COURT FOR THE
WESTERN DISTRICT OF OKLAHOMA

FILED

JUN 27 1989

[illegible]
CLERK, U. S. DISTRICT COURT
BY ______________
DEPUTY

CARLTON JOHNSON by SHARON JOHNSON,)
as his next friend, et al.,)
)
Plaintiffs,)
)
v.) No. CIV-85-3434-A
)
RICHARD H. GROSS, M.D., in his)
individual capacity, et al.,)
)
Defendants.)

O R D E R

Before the Court in this case is defendants' joint motion for partial summary judgment. Defendants seek partial summary judgment under Fed. R. Civ. P. 56(d) on plaintiffs' claims for injunctive and declaratory relief on the ground that the discriminatory practices of which plaintiffs complain do not represent an ongoing harm, and are incapable of repetition. The defendants against whom only injunctive and declaratory relief is sought also seek dismissal from this action.

Plaintiffs bring this action both on their own behalf and on behalf of all children with myelomeningocele who have been, are, or may in the future be evaluated or treated by the myelomeningocele team or its members at Oklahoma Children's Memorial Hospital (OCMH), and on behalf of their parents and legal guardians. Amended Complaint, p. 6, para. 32. Plaintiffs' allege that defendants, medical service providers and administrators at OCMH, and others, discriminate against infants born with myelomeningocele by basing treatment decisions on non-medical social and economic criteria, such as the family's economic and intellectual resources, geographic location of their home, and the child's projected intellectual capacity. Plaintiffs allege that the use of such criteria constitutes discrimination in violation of their substantive and procedural due process rights, and rights to equal protection under the Fourteenth Amendment. Causes of action 1-8 of plaintiffs' First Amended Complaint seek declaratory and injunctive relief, as well as monetary damages. These causes of action pray that the Court both declare that defendants have engaged in unlawful conduct and also enjoin defendants from further engaging in such conduct.

(1) Injunctive Relief

A claim for injunctive relief is appropriate only where a plaintiff demonstrates that he faces a risk of continuing harm. Evidence of past injury alone is insufficient to warrant an injunction. Palmer v. City of Chicago, 755 F.2d 560, 572 (7th Cir. 1985); O'Shea v. Littleton, 94 S.Ct. 669, 676 (1974). In addition, to maintain a claim for injunctive relief a plaintiff must show more than a mere speculative or theoretical possibility of future harm. There must be some realistic likelihood that the alleged past harm will be repeated. City of Los Angeles v. Lyons, 103 S.Ct. 1660, 1668-1670 (1983).

The Court finds that plaintiffs have failed to show any more than a speculative possibility of future discriminatory treatment by defendants, either with respect to the named plaintiffs, or with respect to present and future infants with myelomeningocele who will be evaluated by defendants. Although this case has been pending over three years, and extensive discovery has been conducted, plaintiffs have produced no evidence that defendants have engaged in any selective discriminatory treatment of newborns since 1984. On the contrary, the undisputed evidence submitted by defendants reveals that all newborns under defendants' care since 1984, with the exception of one for whom surgical treatment would have been futile, have received aggressive treatment. See Summary of Defendants' Answers to Interrogatory No. 19, Exhibit 3, Defendants' Motion. This evidence strongly suggests that any unlawful discrimination practiced by defendants has long since ceased. Reasonable jurors could not find that defendants pose a risk of continuing harm to children with myelomeningocele presenting at OCMH. Fed. R. Civ. P. 56(c) mandates the entry of summary judgment, after adequate time for discovery, against a party who has failed to make a sufficient showing on an essential element of her case with respect to which she has the burden of proof. Celotex Corp. v. Catrett, 91 L.Ed.2d 265, (1986); Anderson v. Liberty Lobby, Inc., 106 S.Ct. 2505 (1986).

Plaintiffs' argument in support of their proposition that a factual issue exists as to whether discriminatory medical treatment is ongoing is unpersuasive. Plaintiffs rely on deposition testimony by Cara Madison, Cheparney Camp, and Frieda Smith, relatives of the infant plaintiffs in this case, that, prior to the filing of this action, defendants denied them any real choice as

to treatment of their children. This evidence, however, relates only to defendants' past conduct at the time defendants were evaluating the named plaintiff infants. It does not constitute evidence of any existing or future threat of unlawful conduct for which an injunction might lie.

With respect to the risk of future harm to the named plaintiffs in this case, both Melissa Camp and Stonewall J. Smith are deceased. Injunctive relief as to them is therefore clearly inappropriate. Carlton Johnson, however, is surviving and remains an outpatient at OCMH. Although Carlton Johnson has been under defendants' care since his birth in September 1983, plaintiffs have produced no evidence of discriminatory medical treatment of him since October, 1983. Plaintiffs' evidence of a continuing threat of harm to Carlton Johnson consists entirely of unsubstantiated and inadmissible statements of opinion, not based on personal knowledge, by Sharon Johnson, Carlton Johnson's mother. Plaintiffs' Response Brief, p. 10-11. Such statements are not competent evidence for resisting summary judgment on defendants' claims for injunctive relief. Based on the evidence before the Court, reasonable jurors could not find that Carlton Johnson presently faces a realistic likelihood of future discriminatory treatment by defendants.

(2) Declaratory Relief

Having resolved the injunctive relief issue, we now turn to plaintiffs' claims for declaratory relief. The Declaratory Judgment Act is enabling act, which confers a discretion on the court, rather than an absolute right on the litigant. *Green v. Mansour*, 88 L.Ed.2d 371, 379 (1985); *Public Service Comm. v. Wycoff Co.*, 73 S.Ct. 236, 239 (1952).

The Court in its discretion declines jurisdiction over plaintiffs' declaratory relief claims for several reasons. First, declaratory relief is appropriate only where the facts show "a substantial controversy . . . of sufficient immediacy and reality to warrant the issuance of a declaratory judgment." *Maryland Casualty Co. v. Pacific Coal & Oil Co.*, 85 L.Ed. 826, 829 (1941). As seen above in our discussion of injunctive relief, plaintiffs have failed to show that their controversy retains a quality of immediacy due to an imminent threat of harm.

Second, the declaratory judgment remedy is ordinarily limited to cases where the rights to be protected have not yet been invaded, or where the wrongs to be prevented not yet committed to the extent of actionable damage. Where the wrongful acts complained of have already been committed and the cause of action already exists, declaratory relief will not lie. 26 C.J.S. Declaratory Judgments §17 (1956); *Cincinnati Shoe Mfg. Co. v. Vigorith*, 212 F.2d 583 (6th Cir. 1954). Plaintiffs in this case are complaining that their rights have already been violated by wrongful acts already committed by defendants.

Third, a declaratory judgment proceeding is primarily intended to construe the meaning of a law, not to determine the existence of controverted facts. A court should ordinarily refuse a declaratory judgment which can be made only after a judicial investigation of disputed facts. *United Mine Workers of America v. Roncco*, 314 F.2d 186 (10th Cir. 1963), *on remand*, 232 F.Supp. 865 (D. Wyo. 1964); *Allstate Ins. Co. v. Philip Leasing Co.*, 214 F.Supp. 273, 276 (W.D. So. Dakota 1963). The present case will turn largely on questions of fact to be resolved at trial. A crucial fact question is whether defendants in fact applied discriminatory criteria in selecting infants for beneficial treatment. Such fact questions make declaratory relief inappropriate in this case.

Finally, the declaratory judgment remedy is ordinarily not appropriate where another equally or more important remedy is already available for the issues or rights sought to be determined or declared. *Employers' Liability Assurance Corp. v. Mitchell*, 211 F.2d 441, 443 (5th Cir. 1954). This is particularly so where the case is already ripe for relief by such remedy. *Dresser Industries, Inc. v. Insurance Co. of No. America*, 358 F.Supp. 327, 330 (N.D. Tex 1973), *aff'd*, 475 F.2d 1402 (5th Cir. 1973). Plaintiffs have a fully adequate remedy for their alleged wrongs in their claim for monetary damages. The existence of this remedy makes declaratory relief unnecessary in this case.

Conclusion

For the above stated reasons, defendants are hereby granted summary judgment on plaintiffs' claims for injunctive and declaratory relief. Fed. R. Civ. P. 56(d). Consequently, those defendants against whom only injunctive or declaratory is sought, defendants Reginald Barnes, William Barnes, Chandler, Coussons, Doenitz, Eaton, Farhas, Furr, Greer, Hargis, Harris, Hartley, Kidd, Orr, Padilla, Stafford, Sullivan, Tatyrek, Toule, Tull, Walters, Watson, Yngve, and Children's Shelter, Inc. are hereby DISMISSED WITH PREJUDICE from this action.

Remaining for trial in this case are plaintiffs' claims for monetary damages against defendants Craig, Gross, Herbeck, Houdesheldt, Livington, Morris, Olson, Pratt, Razook, Stuemky, and Thompson.

It is so ordered this 27th day of June, 1989.

Wayne Alley
WAYNE E. ALLEY
United States District Judge

Entered in judgment docket 6-29-89

Montefiore

Montefiore Medical Center

111 East 210th Street
Bronx, New York 10467
212 920 6736

In association with
Albert Einstein College of Medicine

Office of Legal Affairs

VIA FEDERAL EXPRESS

November 11, 1988

William J. Howard
General Counsel
United States Commission
on Civil Rights
1121 Vermont Avenue, N.W.
Washington, D.C. 20425

re: Proposed Report on Medical
Treatment of Handicapped Infants

Dear Mr. Howard:

Enclosed is the response of Montefiore Medical Center to an excerpt from a report being prepared by the United States Commission on Civil Rights on the medical treatment of handicapped infants, which was enclosed with your October 19, 1988 letter to Spencer Foreman, M.D., President of Montefiore Medical Center.

We understand that the enclosed response will be published as an appendix to the report, pursuant to P.L. 87-183 (98th Cong. 1st Sess)(H.R.2230).

Very truly yours,

Nadia C. Adler
Vice President -
Legal Affairs
and General Counsel

NCA:bw
Enc.
cc: Spencer Foreman, M.D.
Constance Margolin,
Associate General Counsel

RECEIVED
11-14-88

[A:INFANTS/B18]

Henry and Lucy Moses Division
The Jack D. Weiler Hospital of the
Albert Einstein College of Medicine
Beth Abraham Hospital
Family Health Center
Loeb Center Skilled Nursing Facility
Montefiore Home Health Agency

Montefiore Medical Group
Montefiore Comprehensive Health Care Center
Montefiore-Rikers Island Health Services
Valentine Lane Family Practice
Affiliated with
North Central Bronx Hospital
Nathan Miller Center for Nursing Care, Inc.

Response of Montefiore Medical Center to Four Typewritten Pages Identified as a Portion of "Chapter 11, Role and Performance of ICRCS," from a Proposed Report by the United States Commission on Civil Rights on the Medical Treatment of Handicapped Infants

This statement is submitted by Montefiore Medical Center ("Montefiore") in response to the four-page excerpt from the above-referenced Report, which the United States Commission on Civil Rights (the "Commission") forwarded to Montefiore for review and comment pursuant to the rules and regulations of the Commission (45 C.F.R. Chapter VII).

Although the Commission furnished only a fragment of its Report to Montefiore, it appears that the purpose of the Report is to evaluate compliance by infant care review committees with the Child Abuse Amendments of 1984 (the "Child Abuse Amendments"), which prohibit the withholding or withdrawal of medical treatment from handicapped infants except under certain circumstances.[1]

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[1] 42 U.S.C. §5012. The Child Abuse Amendments define "child abuse and neglect" to include "medical neglect." 42 U.S.C. §5102. The Child Abuse Amendments and the regulations of the Office of Human Development Services of the Department of Health and Human Services ("HHS") thereunder define "medical neglect" as the "withholding of medically indicated treatment," which, in turn, is defined in the statute and the regulations as "the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions," with certain express exceptions discussed in detail at pp. 6-8, infra. (42 U.S.C. §5102; and 45 C.F.R. Part 1340 and Appendix thereto.)

The excerpt provided to Montefiore focuses on the infant bioethical review committee of Montefiore and the Albert Einstein College of Medicine (the "Einstein-Montefiore Committee"), and proposes to conclude (p. 4) that Committee has "not been attempting to apply" the standards established under the Child Abuse Amendments.

Montefiore takes strong exception to the conclusions asserted in the Report. These conclusions are inaccurate, unfair and have no basis in fact or law. Montefiore is proud of the members of its infant bioethical review committee -- respected and dedicated professionals who have devoted many anguished hours of thoughtful and difficult work to ensure that no disabled infant is denied medically indicated treatment.

The Einstein-Montefiore Committee was established in 1984 as a set of interlocking committees, one for each of Montefiore's hospital divisions and one for each of the two other hospitals affiliated with the Albert Einstein College of Medicine and Montefiore. A core group of experts, consisting of a neonatologist, three other pediatricians with expertise in neonatology, disabilities and rehabilitative medicine; and bioethicists, with an attorney acting as a consultant to the group, serve on each hospital's committee. The individual hospitals appoint nursing, social work, administrative and community representatives to their respective committees.

The Chairman of the Einstein-Montefiore Committee is Alan Fleischman, M.D., Director, Division of Neonatology and Professor of Pediatrics at Albert Einstein College of Medicine and Montefiore Medical Center. Dr. Fleischman is an eminent bioethicist and neonatologist who is actively involved in many organizations dedicated to the care and rights of disabled infants, including the National Bioethics Committee of the American Academy of Pediatrics; the New York State Task Force on Life and the Law; New York Neonatal Technical Advisory Group (to the New York Statement Department of Health); the National Advisory Committee, Project Bridge (U.S. Department of Eduation grant for educating pediatricians about decision-making for disabled infants); and as Chairman for Chapter Grants, March of Dimes. He is the author or co-author of approximately 130 book chapters, articles and abstracts pertaining to neonatology and the care and treatment of disabled infants.

The Einstein-Montefiore Committee chaired by Dr. Fleischman has established a uniform set of principles to guide its members in their deliberations. The principles are intended to assist the Committee members in applying the Child Abuse Amendments to the cases under review. Thus, the principles include explicit statements affirming the intrinsic dignity and worth of every newborn, and provide that all infants, irrespective of disability or handicap, be offered "humane care and appropriate treatment." (See Fleischman, Bioethical Review Committees in Perinatology, 14 Clinics in Perinatology 379 (1987) ("Fleischman"), 384.

In addition, even though mandatory prospective review is not required by federal law, the Einstein-Montefiore Committee has a stated policy of prior review of all cases in which it is proposed that medical treatment be withheld or withdrawn from an infant who is not imminently dying. The Committee's voluntary policy of prospective review clearly adds to the burden of the Committee members, at times requiring Committee members to meet on an emergency basis to consider the needs of a particular infant, but the Committee members view such prospective review as an integral part of their duty to protect disabled infants from denials of medically indicated treatment. It is clear both from the Committee's principles and from its operational procedures that it is dedicated to protecting disabled infants from denial of medically indicated treatment.

It is also clear from the records of Montefiore's Division of Neonatology that not just the Committee, but the neonatology service as a whole, is dedicated to providing medically indicated treatment to disabled infants, and routinely provides that care. In each case, the determinant for treatment is whether, in the reasonable medical judgment of the treating physician, a treatment is available that can ameliorate or correct a life-threatening condition within the meaning of the Child Abuse Amendments. (See pp. 9-10, infra.)

Accordingly, the Office of the Inspector General ("OIG"), the HHS office responsible for auditing compliance with HHS statutes and regulations, has been favorably impressed by the practice and procedures of the neonatologists and the Einstein-Montefiore Committee. In its 1987 study of infant care review committees under the Child Abuse Amendments, OIG singled out the Einstein-Montefiore Committee from among the ten committees reviewed by it nationally, describing the Einstein-Montefiore Committee in some detail, and concluding that it is "generally structured and functioning in conformance with the HHS model guidelines, and may serve as a useful reference for hospitals considering the establishment of similar committees."[2] OIG reached this conclusion based on a full-day on-site visit to Montefiore, in which OIG staff conducted case reviews and interviewed Committee members to get an in-depth understanding of the Committee's work.

By contrast, it appears that the sole source of information relied upon by the Commission to criticize the Einstein-Montefiore Committee is the article written by Dr. Fleischman on infant bioethical review committees, referred to above. Dr. Fleischman's article, however, does not comprise an exhaustive review and report on the work of the Einstein-Montefiore Committee, and a reading of the article cannot substitute for a thorough examination of the Committee's work. In fact, the sole portion of the article discussing in any way the particulars of cases reviewed by the Committee provides only the most cursory summary of eight of the thirty cases reviewed by the Committee in its early years, in a discussion less than one page in length (Fleischman, 388-389).[3]

---

[2] Office of Inspector General, U.S. Dept. of Health and Human Services, Infant Care Review Committees Under the Baby Doe Program (1987), 11.

Distilled to essentials, the excerpt from the Commission's Report suggests that the Einstein-Montefiore Committee fails to adhere to the Child Abuse Amendments because, as stated in Dr. Fleischman's article, it has permitted treatment to be withheld in some cases. However, the Child Abuse Amendments do not make it unlawful to withhold or withdraw treatment, but only to withhold or withdraw medically indicated treatment. The sheer fact of a denial of treatment in any given case is without legal significance. No inference, much less conclusion, of illegality can be drawn from a denial alone. A finding of illegality must turn on the detailed facts of each individual case, to determine whether the treatment was medically indicated, including whether the denial failed to fit within explicit regulatory provisions permitting treatment to be withheld or withdrawn.

The Child Abuse Amendments and the federal regulations promulgated thereunder explicitly authorize the withholding or withdrawal of treatment under the following circumstances:

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[3] It should be noted that Dr. Fleischman's article, which was not intended to be a comprehensive exposition of the Committee's work, provided minimal information about the cases discussed in order to preserve the confidentiality of patient information.

> "when, in treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant' or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane." (42 U.S.C. §5102(2)(B)(3), 45 C.F.R. §1340.15(b)(2).)

To provide guidance to health care providers as to when the Child Abuse Amendments permit the withholding of treatment, HHS issued guidelines which state, inter alia, that the phrase "the treatment itself under such circumstances would be inhumane" in subsection (C) means that "the treatment itself involves significant medical contraindications and/or significant pain and suffering for the infant that clearly outweighs the very slight potential benefit of the treatment for an infant highly unlikely to survive." (45 C.F.R. §1340.15, Appendix, p. 222.)

The Child Abuse Amendments and the regulations thereunder expressly defer to the "treating physician's (or physicians') reasonable medical judgment" to determine what treatment "will be most likely to be effective in ameliorating or correcting all [of the infant's] life-threatening conditions" or whether other circumstances exist to permit a withholding of treatment under one of the statutory exceptions. (42 U.S.C. §5102; 45 C.F.R. Part 1340, Appendix, p. 217.) In other words, Congress and HHS have made clear that the determination as to what, if any, treatment is medically indicated, is to be left to the professional judgment of the treating physician(s). Given that medical judgments are key to decision-making under the Child Abuse Amendments, it cannot responsibly be suggested that the Committee has violated the Child Abuse Amendments, simply on the superficial observation that medical treatment has been withheld.

Dr. Fleischman's comments on the Committee's decision-making process, cited by the Commission on the second page of the Report excerpt, are entirely consistent with the Child Abuse Amendments, which make medical judgments the key to the propriety of treatment decisions. (45 C.F.R. Part 1340, Appendix.) In discussing the categories of decisions that arise, Dr. Fleischman, as an expert neonatologist, merely observes that in some instances -- in the "grey area" cases -- reasonable medical judgments may differ concerning which of the judgments as to treatment and the infant's condition best protect the infant (e.g., whether the infant should be treated when there are conflicting medical judgments as to the effectiveness of the treatment to ameliorate or correct the life-threatening condition, or when there are reasonable differences among the treating physicians as to whether the very slight benefit to the infant will be outweighed by the pain and suffering that the treatment will bring to the infant). In such cases, the Committee has not abdicated its role. Rather, in the exercise of its duties the Committee has determined that, based on reasonable medical judgment, selection of any of the treatment options (including the option not to treat) would be a reasonable exercise of medical judgment, and not "medical neglect." That threshhold determination having been made, the Committee then permits the parents (or Child Protective Services Agency, as appropriate) to decide among the available options in the infant's best interests.

The Report excerpt itself implicitly recognizes that the mere withholding of treatment does not demonstrate or even raise a question of illegality, when it seeks to justify its proposed conclusions by reference to "context." The context to which the Report excerpt refers is the thirty cases that the Committee reviewed in its early years, noted in Dr. Fleischman's article (pp. 388-389) in only the most superficial and summary fashion. We submit that this is not the appropriate context. The proper context, which the Report excerpt ignores, must be the full details of the treatment provided to (or withheld from) all disabled infants at the hospitals served by the Committee, and not just the treatment provided in the cases coming before the Committee.

Montefiore is a tertiary care institution which provides highly technical treatment and supportive care for about 1,200 infants annually in its affiliated neonatal intensive care units. It is a place to which extremely ill and disabled infants are brought expressly because of the technologically advanced, quality care that is offered to them. For example, on a weekly, if not daily, basis the Einstein-Montefiore staff assumes that medical and/or surgical treatment is appropriate, and thus regularly provides that treatment in the following categories of cases: (i) to infants suffering from genetic abnormalities (Down's Syndrome and other similar disorders), who are given respiratory support or receive surgery for congenital bowel and/or heart abnormalities (4-6 such infants per year); (ii) to premature infants with severe intraventricular hemorrhage (almost certain to develop cerebral palsy and mental retardation), who are treated medically and surgically for respirator dependence or necrotizing enterocolitis; and (iii) to infants who are born with multiple congenital abnormalities, such as encephaloceoles, myelomeningocoeles, gastroschisis, spinal deformaties, or gastro-intestinal, renal or cardiac disorders, whose life-threatening abnormalities are aggressively treated and managed by the neonatal service. In most of the cases of infants with potential disabilities, of which there are hundreds each year, there is never an issue for the Committee to consider, because the neonatologists routinely provide medically indicated treatment. Indeed, in a tertiary care center such as Montefiore, where professional expertise and technological capabilities create treatment options not available in other settings, highly specialized life-saving treatment is the routine, and is provided as a matter of course to save the lives of infants with potential disabilities.

It is in this larger context of dedicated care to hundreds of infants with potential disabilities that it is most inappropriate to rely, as the Report excerpt does, on Dr. Fleischman's terse references to three particular cases for criticism of the Einstein-Montefiore Committee. Moreover, even the Commission's discussion of these three cases fails to support the conclusions reached in the Report excerpt.

In the first case discussed in the Report, the Commission notes that the Einstein-Montefiore Committee referred the infant's case to the state child protective services agency because "the attending physician believed treatment should be provided and the parents disagreed." (Report excerpt, p. 2.) The Report implies that the Einstein-Montefiore Committee took a neutral stance and was attempting to evade responsibility. In fact, however, the Committee supported the attending physician, and "the help of the Child Protection Services Agency was invoked to override parental refusal of surgery" -- details clearly stated in Dr. Fleischman's article (p. 389, emphasis added) and omitted from the Report excerpt. Moreover, the Child Abuse Amendments expressly require that such a referral be made, as a procedure for ensuring that medically indicated treatment will be provided to the infant regardless of the parents' wishes. (42 U.S.C. §5103.) The Committee was manifestly acting in complete compliance with the Child Abuse Amendments in making that referral, and the Child Protective Services Agency successfully relied on the Committee's recommendation for treatment to ask a court to order treatment in the interest of the infant.

With respect to the second case, the Report excerpt accurately states that the Einstein-Montefiore Committee persuaded the treating physician and parents that treatment should be provided even though the treating physician and parents had originally objected to such treatment. Reference to this case hardly supports the Report excerpt's assertion (p. 4) that the Committee operates to "bless denials" of treatment.

Even in the third case, where the treating physicians and the Committee concluded that treatment should not be given despite the parents' wish to have it provided, it cannot be said that the infant was denied medically indicated treatment in violation of the Child Abuse Amendments. On the contrary, surgery simply would not have saved or prolonged the infant's life. As Dr. Fleischman's article plainly states, a retrospective review of the case (the infant was imminently dying and indeed died before the Committee could be convened for prospective review) indicated that the parents' wish to provide treatment would have imposed "undue pain and suffering on an infant for no potential benefit." (Fleischman, p. 389.) The Report, once again, omits this detail. In point of fact, the Child Abuse Amendments, as shown above, permit treatment to be denied when it would "not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or [would] otherwise ... be futile in terms of the survival of the infant" -- i.e., the circumstances of this particular case. Indeed, even if treatment would be of slight benefit, the Child Abuse Amendments allow treatment to be foregone if "the treatment ... involves ... significant pain and suffering for the infant that clearly outweighs the very slight potential benefit of the treatment for an infant highly unlikely to survive." (45 C.F.R. §1340.15(b)(2).)

After concluding its discussion of the three cases briefly noted in Dr. Fleischman's article, the Report excerpt states (p. 3) that "[I]n all the other cases the Committee agreed with the desire of physicians and parents to withhold treatment," citing Dr. Fleischman's article for this proposition. First, the citation is inaccurate. In fact, the article indicates that in at least two of eight cases involving neonates in the first days of life, the decision to withhold treatment was overridden by the intervention of the Committee, once without the need to secure the aid of the Child Protective Services Agency, and once with such aid where the parents continued to resist treatment notwithstanding the Committee's intervention. (Fleischman 388-389.) As to "all the other cases," the actual comment made by Dr. Fleischman about them is as follows, quoted in full and without ellisions: "In all of the other thirty cases including one in which the help of the Child Protective Services Agency was invoked to override parental refusal of surgery, it is highly likely that the same outcomes would have occurred prior to the existence of our infant bioethical review committee."

(Fleischman, 389.) Moreover, quite apart from the inaccuracy of the citation, the Child Abuse Amendments expressly permit the withholding or withdrawal of medical treatments under certain circumstances, as shown above. The mere fact of withholding or withdrawing treatment does not support the Report's assertion (excerpt, p. 3) that "the Committees are not serving their function."

In addition to its reliance on references to cases only briefly noted by Dr. Fleischman, which reliance is misplaced, the Report seems to find objectionable Dr. Fleischman's discussion of the fact that the Committee's involvement eases the psychological distress of nurses and family members in making agonizing decisions about the rendition of treatment to severely disabled infants. Here, too, the objection is not well taken. This by-product of the Committee's functioning is entirely consistent with lawful and ethical execution of the Committee's duties.

Indeed, the Report excerpt in its last sentence ultimately recognizes that the minimal information before the Commission is insufficient to support any conclusion of illegality, noting that the Commission cannot really determine that any treatment denials violated the Child Abuse Amendments because the Commission does not have the actual facts. (Report excerpt, pp. 3-4.)

Notwithstanding the acknowledged absence of evidence, the Report excerpt (p. 4) startlingly goes on to pronounce that "the

Committees have not been attempting to apply those standards [established by the Child Abuse Amendments]." The basis for this extraordinary conclusion -- which the Report self-servingly declares to be "clear" and "fair" -- is that Dr. Fleischman's article referred to principles that the Committee has found to be helpful in its deliberations and discussions, and that one of these principles is that "'[w]ithholding or withdrawing treatment may be considered when the medical treatment imposes a burden that lacks compensating benefits for the infant.'" (Report excerpt, p. 4.) As shown above (pp. 7, 12-13), the Child Abuse Amendments and the regulations and HHS guidelines thereunder clearly permit the weighing of the benefits and burden to the infant to ensure that the Committee protects the disabled infant from "inhumane treatment." The mere fact that the principle permits the Committee to utilize a balancing standard in certain circumstances does not, by itself, constitute a violation of the Child Abuse Amendments. The Commission is not aided in this regard by its speculative assertion -- without any basis in fact -- that the Committee's recommendations are based on other than the criteria set forth in the Child Abuse Amendments and the regulations and HHS guidelines thereunder.

Nor is the Commission able to carry its burden of demonstrating that there have been violations of the Child Abuse Amendments merely by out-of-context quotes from Dr. Fleischman's article, particularly in view of the fact that the Einstein-Montefiore Committee's activities have been carefully examined by the OIG and held up as a model for other infant care review committees. In contrast to the superficial basis for the Report excerpt, OIG personnel spent a full day on-site, interviewing Dr. Fleischman and other members of the core Committee and reviewing cases. OIG staff were also provided with an advance print of the very article by Dr. Fleischman upon which the Commission bases its criticism of the Einstein-Montefiore Committee, but, following its thorough review of the Einstein-Montefiore Committee, OIG reached a far different conclusion from the Commission.

In sum, the Einstein-Montefiore Committee is a first-rank infant care review committee, comprising dedicated, compassionate medical and other professionals devoted to providing infants, including those who are potentially disabled, with high quality, appropriate, humane medical care consistent with applicable law. The proposed conclusions of the Report excerpt are erroneous and unsupportable, and we respectfully urge that they be re-evaluated and withdrawn.

The foregoing statement is made on information and belief, and I believe the matters stated herein to be true.

Nadia C. Adler
Vice President & General Counsel
Montefiore Medical Center

Sworn to before me this
11th day of November, 1988

Constance B Margolin
Notary Public
CONSTANCE B. MARGOLIN
Notary Public, State of New York
No. 02-4888207
Qualified in Westchester County
Commission Expires March 9, 1989

BLOOMINGTON OBSTETRICS AND GYNECOLOGY, INC.

WALTER L. OWENS, M.D.
WILLIAM R. ANDERSON, M.D.
LELAND R. MATTHEWS, M.D.
BRANDT L. LUDLOW, M.D.
DWIGHT L. STAUFFER, M.D.
ALICE B. WOOD, M.D.
MADREAN SCHOBER, R.N.C.
NURSE PRACTITIONER
SUELLEN MOYNIHAN
OFFICE MANAGER

(812) 336-0168
421 WEST FIRST STREET
BLOOMINGTON, INDIANA 47401

September 16, 1988

William J. Howard
General Council
United States Commission on Civil Rights
1121 Vermont Avenue Northwest
Washington D.C. 20425

Dear Mr. Howard,

Thank you for enclosing portions of the report of the Commission on Civil Rights. The conclusions appear to be out of touch with reality, but much of what goes on in Washington D.C. is out of touch with reality.

This is merely one of the many facets in which medical technology has moved faster than the ability of society to accommodate and to reach a reasonable consensus. Time will tell.

Meanwhile, Baby Doe died with little suffering after a few days. A family which probably would have been destroyed by the situation has not only been preserved, but they have had another very healthy child, which almost certainly would never have been born, had the pediatricians been able to enforce treatment to preserve Baby Doe's life.

My conscience is clear. I am proud to have stood up for what I and a large percentage of people feel was right. I have asked my children to make sure that my grandchildren know of their grandfather's role in this case and that he had the honor of a personal denunciation by Ronald Reagan.

BLOOMINGTON OBSTETRICS AND GYNECOLOGY, INC.

WALTER L. OWENS, M.D.
WILLIAM R. ANDERSON, M.D.
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(812) 336-0168
421 WEST FIRST STREET
BLOOMINGTON, INDIANA 47401

Meanwhile, I hope that you and the commission members may have the privilege of living in blissful isolation from the hard decisions of real life.

Sincerely yours,

Walter L. Owens

Walter L. Owens, M. D.

WLO/sm

Suellen T. Moynihan
Suellen T Moynihan

County of residence: Monroe
Date of expiration 5/15/92

Viewpoint

The Right to Life

BY GEORGE CRILE, JR., M.D.

THE LAW NOW STATES that in obstetrical units, babies must be fed and given full support, regardless of how extensive and hopeless their congenital malformations.

Despite the law, the debate about the "right to life" continues, involving not only newborn babies but the morality of contraception and abortion, the question of capital punishment, and in patients with damaged brains, the problem of when, if ever, to "pull the plug." These must be viewed not only in the light of the individual's right to life, but in that of society's right for its members to have productive and pleasant lives, not to be lived mainly to support the growing numbers of hopelessly disabled, often unconscious people whose costly existence is consuming so much of the gross national product.

Let's start at the beginning. In the days before vaccination and antibiotics, infectious diseases, like smallpox and diphtheria, killed so many children, and so many more died as young adults of tuberculosis that there was little reason to consider contraception as a means of controlling population. The church opposed birth control and abortion because then there was no threat of overpopulation and it was good to have the members have children to rear in the principles of the church.

In the last 80 years, most of the old rules have changed. Life expectancy in America has increased from 47.3 years in 1900 to 73.3 years in 1980. The population of the world has similarly increased from 1,200,000,000 in 1900, to 4,269,000,000 in 1978. Most of this increase occurred since 1950.

Nature has endowed healthy adults with an inextinguishable sexual desire. Therefore, it seems obvious that the results of sexual activity must be controlled or within a century the exponential growth of the population will result in disaster. Most of the world has recognized this fact and has approved of or even enforced contraception and abortion. Today, in most of China, only one child per couple is allowed. The economic penalties for more (except for twins) are severe. In view of current worldwide trends, there is little need to argue the cause of birth control. Whether we like it or not, it is a fact and, legally or illegally, will continue.

Next in the sequence of disasters is the baby born with incurable defects that make it unable, ever, to support itself or to be anything but a sorrow to its parents and a drain on the economy. I am not referring to defects that can be treated—harelips, spina bifidas, or deformities of the extremities, all of which can be corrected or compensated for by surgery. I am concerned about the disposition of those babies who have irreversible brain damage or totally incurable and accurately diagnosable brain defects such as Down's syndrome. No child with Down's syndrome ever grew up to be self-sustaining. Twenty years ago the diagnosis was a matter of clinical judgment; sometimes it was wrong. Today, the diagnosis is accurate, made on the basis of the chromosomes. As a result, parents can be told that their child has no chance of growing up to be able to take care of itself. If the parents still want to rear their child, that should be their decision, but there should be no support from the community or the state.

I wish to emphasize that I do not believe that existence is necessarily unhappy for the child with Down's nor that such a child cannot be a joy to its parents. That is why the parents should make the final decision.

It remains that a child with Down's syndrome, proven by examination of the chromosomes, will not grow up to be self-sustaining or able to contribute to the economy. Neither the community nor taxpayers should be obliged to support the child.

A different situation exists in respect to babies born with severe brain damage. There is no certain test to show the extent or reversibility of the damage; therefore a period of observation would be necessary before withdrawal of support could be advised. Several qualified consultants would have to agree before any decision was made. But again, if the decision was to withdraw support, there should be no further obligation for state or community to care for the child. If this were the decision, no medicine would be given the child, no intravenous or artificial feeding.

The Totally Incompetent

Oldsters, with mental deterioration from stroke or Alzheimer's disease, often become totally incompetent to care for themselves or even to feed themselves. These people do not recognize their friends or relatives and are not aware of their surroundings; to live is merely to exist. There should be no reason to support life artificially in these cases or of those who have been unconscious for weeks and whose existence is maintained by heart-lung machines. Again, unanimous approval of qualified consultants could result in withdrawal of artificial support.

At the present time, an unsupportably high proportion of all Blue Cross and Medicare funds are spent on a small group of helpless patients who require constant and expensive care. Although there are many ways that the cost of health care could be reduced, one of the simplest would be, in professionally approved cases, to let nature take its course.

Dr. Crile, Jr., is emeritus consultant and former head, department of general surgery, Cleveland Clinic, Cleveland, Ohio

George Crile, Jr., M.D.
2060 Kent Road
Cleveland Hts., OH 44106

September 15, 1988

William J. Howard
US Commission On Civil Rights
1121 Vermont Avenue
Suite 800
Washington, D.C. 20425

Dear Mr. Howard:

The quotation that was used to indicate that I do not approve of the rehabilitation of disabled persons was lifted out-of-context and for this reason it gives a false impression of my stand. I have never stood against rehabilitation of any one with a brain that was functional or a body that was salvageable. I clearly state in my article that I am referring to people who are hopelessly disabled, and that means disabled to the extent that rehabilitation could not help them to improve or recover. I also state that there is no use in prolonging the lives of those who are unconscious as a result of prolonged coma from which there is no chance of recovery.

If the authors of this treatise do not 1) Omit the out-of-context quotation from my article or 2) Reprint all of my article or 3) Publish this criticism of their out-of-context quote, I will be forced to discuss this misrepresentation with my attorney.

Again, may I emphasize that it is not rehabilitation that I stand against, it is the costly attempts to rehabilitate those for whom there is no hope.

Sincerely yours,

George Crile Jr.

George Crile, Jr., M.D.

GC/eg

Sworn to before me and subscribed in my presence this 15th day of September 1988. My Commission expires ______.

RECEIVED
9-19-88

Joanne Prusinski
Notary Public

JOANNE PRUSINSKI, Notary Public
State of Ohio
My commission expires Aug. 15, 1993
Recorded in Cuyahoga County

Yale New Haven Hospital
1826
20 York Street, New Haven, CT 06504

JOHN E. FENN, M.D.
CHIEF OF STAFF

October 6, 1988

William J. Howard, Esq.
General Counsel
United States Commission on Civil Rights
1121 Vermont Avenue, N.W.
Washington, D.C. 20425

Dear Mr. Howard:

Thank you for your letter of September 13, 1988.

The allegations you mention about the withholding of treatment to newborns, including references to articles by Dr. Duff written in the 1970s and newspaper stories in the Hartford Courant in 1981, were thoroughly investigated by the Hospital, the U.S. Department of Health and Human Services (HHS), and the Connecticut Department of Health Services, and resolved in favor of the Hospital.

These allegations, moreover, are obviously quite dated. We provide what I believe to be outstanding services to newborns; it is our mission to treat children, not to withhold treatment. It would be unfortunate to rehash these old allegations -- proven not to have substance -- and thereby damage the reputation of the Hospital and its physicians.

It might be helpful to begin by relating to you the history of the investigations.

Beginning in June, 1981, the Hartford Courant ran a series of articles about newborn care. On June 23, 1981, the Connecticut Department of Health Services announced its investigation of the Hospital. On June 24, 1981, former Connecticut State Senator Regina Smith filed a complaint with HHS. On July 27, 1982, the Hospital received a letter from HHS announcing a civil rights compliance review of the Hospital.

The first federal investigators arrived on September 14, 1982. During the fall of 1982, HHS personnel reviewed over one hundred charts of deaths between January and June, 1981, and March through August, of 1982. They subsequently reviewed 110 charts of babies with specified conditions admitted between October, 1979, and December, 1982. They also conducted extensive interviews with Hospital physicians, nurses, social workers, administrators, and others. On November 10, 1982, the Pediatrics Department Guidelines, which already were in place and which implicitly rejected Dr. Duff's personal views, were adopted by the Board of Trustees as official Hospital policy. In March, 1983, OCR Investigator Peter Chan returned to the Hospital for additional interviews with physicians. On July 21, 1983, Investigator Chan again met with representatives of the Hospital requesting additional information.

On February 1, 1983, the investigation broadened into an investigation of whether or not any of the policies of the Hospital violated Section 504 of the Rehabilitation Act of 1973, as amended. From approximately that time on, the matter was referenced as HHS OCR Compliance Review No. 01-82-7002.

On August 16, 1984, HHS's Office for Civil Rights (OCR) proposed a "Compliance Plan" to finally resolve the entire matter. It was viewed by the government as a "voluntary action plan." During the next several months, details of this settlement were successfully worked out by the government and the Hospital.

On December 5, 1984, Ms. Chang, the OCR Regional Manager, wrote to the Hospital, concluding that during the on-site review, OCR concluded, inter alia, that:

> Yale-New Haven Hospital's policies and procedures regarding patient admissions, room assignments and transfers, and the granting of staff privileges were in compliance with Title VI. Contacts with community and advocacy groups did not disclose any allegations of violations; and
>
> YNHH had designated a Section 504 coordinator pursuant to 45 C.F.R. §84.7(a).

OCR also determined several minor problem areas involving, in its view, inadequate notice and grievance policies, and the need for more specific policies with regard to sign language interpreters. YNHH has adopted a Nondiscrimination Plan signed by its Chief of Staff, dated November 19, 1984.

With respect to handicapped infants, Ms. Chang indicated that the matter would not be pursued further because of legal considerations. She concluded her letter by thanking the Hospital for its cooperation and the assistance rendered to her investigators.

It should be noted that the State investigation also had been resolved in favor of the Hospital. From the beginning of the investigations, the Hospital denied allegations of any wrongdoing, and pointed out that the Pediatric Department had not accepted Dr. Duff's point of view, but had rejected it and adopted its own guidelines.

During the course of the investigations, the government and the Hospital spent thousands of hours working on the matter, at a substantial cost to the parties both in terms of manpower and money.

I hope that I have adequately responded to your inquiry. It would be unfortunate if the same stale and fully explored territory were to be revisited after so much time and effort have been devoted to resolving the issues involved, hopefully forever. We are proud of our outstanding newborn special care unit, which over the years has saved thousands of lives. To reopen this matter not only would be unfair and inappropriate, but could damage the reputation of the Hospital and its physicians.

We hope that, based on the information provided in this letter, you will decide not to include any reference to Yale-New Haven Hospital (or any of its physicians or former physicians) in your report or in any other document(s). If, however, such reference is made, we request that this letter also be incorporated in order to provide readers with the full story.

Thank you very much for your consideration of this information.

Sincerely yours,

John E. Fenn

John E. Fenn, M.D.

JEF:pm

cc: Mr. C. Thomas Smith

Subscribed and Sworn to before me, a Notary Public, in and for County of New Haven and State of Connecticut, this 7th day of October 1988

Notary Public

My Commission Expires Mar. 31, 1993

UNITED STATES
COMMISSION ON
CIVIL RIGHTS

1121 Vermont Avenue, N.W.
Washington, D.C. 20425

October 7, 1988

John E. Fenn, M.D.
Chief of Staff
Yale New Haven Hospital
20 York Street
New Haven CT 06504

Dear Dr. Fenn:

Thank you for your letter of October 6, 1988.

It would be very helpful to the Commission, in assessing whether the tentative material to which you responded should be modified, to have copies of four items referenced in your letter.

These are:

> The Pediatric Department Guidelines adopted by the hospital Board of Trustees on November 10, 1982.
>
> The "Compliance Plan" proposed by the HHS Office for Civil Rights on August 16, 1984.
>
> The final settlement based on this compliance plan "worked out by the government and the Hospital."
>
> The December 5, 1984 letter from Ms. Chang, OCR Regional Manager.

Finally, does the hospital regard the final settlement referred to in your letter as currently in effect and binding on the hospital? Is the hospital now in fact in compliance with all aspects of the settlement?

To ensure that the final report will fully reflect consideration of this information, it would be helpful if you could supply it as soon as conveniently possible, preferably by October 14, 1988.

The Commission will give very careful consideration to the information contained in your letter and to the material you send in response to this request in determining whether and in what manner to modify the text on which you have commented

Thank you very much for your cooperation in this matter.

Sincerely,

William J. Howard

WILLIAM J. HOWARD
General Counsel

Yale New Haven Hospital
1826
20 York Street, New Haven, CT 06504

JOHN E. FENN, M.D.
CHIEF OF STAFF

October 18, 1988

William J. Howard, Esq.
General Counsel
United States Commission on Civil Rights
1121 Vermont Avenue, N.W.
Washington, D.C. 20424

Dear Mr. Howard:

This is in response to your letter of October 7, 1988, and in supplement to my letter to you of October 6, 1988.

First, as previously indicated, all of the matters at issue have been resolved in favor of the Hospital. We respectfully repeat our request that no reference to the Hospital or its physicians be made in your report or in any other document, and that, if such reference is made, my letter of October 6, 1988, and this letter, be incorporated into the report or other document in order to provide readers with the full story.

I enclose copies of the four documents requested in your letter of October 7, 1988.

In answer to your question, the Hospital continues to exercise its best effort to be in compliance with all requirements of law and its final settlement agreement.

Finally, I emphasize that to reopen a matter which has been explored fully and resolved to the satisfaction of the Hospital, the Connecticut Department of Health Services, and the U.S. Department of Health and Human Services, could serve only to damage the reputation of the Hospital and its physicians and could impede our ability to continue in the provision of outstanding service to newborns. As previously indicated, it is our mission to treat children, not to withhold treatment.

Sincerely yours,

John E. Fenn

John E. Fenn, M.D.

JEF:pm
Enclosures

cc: C. Thomas Smith

YaleNewHavenHospital

1826

789 Howard Avenue
New Haven, Connecticut 06504

GUIDELINES FOR DECIDING CARE OF CRITICALLY ILL PATIENTS

These guidelines are designed to provide direction in the management of critically ill children at Yale-New Haven Hospital. They will be made available to all members of the medical, nursing, and social work staffs.

They are predicated on the assumption that every child treated in this hospital will have maximal efforts utilized to maintain life and health, except in those unusual circumstances where such effort is not indicated or justified. They are also predicated on the assumption that everyone caring for sick children in this institution is well aware that "active euthanasia," any active intervention which will inevitably result in the death of a patient, is illegal, contrary to medical ethics, and intolerable.

The Attending Physician and the parents have the primary responsibility for making decisions about the care of a child. Various other care providers and family counsellors can, and should, contribute to these decisions when appropriate, but the final authority rests with the Attending Physician and the parents to formulate and implement management. Any concerned person involved in the care of the child who disagrees with that decision may appeal to the Chief of the Department of Pediatrics who will attempt to resolve the differences of opinion.

To clearly define patient care, three categories of clinical management have been established:

Class A: Maximal therapeutic effort with no reservations.

This group will include most children in Yale-New Haven Hospital, including patients for whom there are significant uncertainties about diagnosis or prognosis. All patients will be assigned to this category unless specified otherwise. For patients in this category, all available efforts will be extended to preserve life and to restore the patient to health.

Class B: Selective limitation of therapeutic measures.

For patients in this category, all usual components of therapy will be employed but heroic, extensive, and highly sophisticated measures to prolong life will be withheld because the ultimate prospects for recovery are negligible.

The clearest example of a patient in this category is the decision not to perform extensive resuscitation in a terminal situation (i.e. a child with end stage leukemia refractory to therapy who may have respiratory arrest may be assigned to Class B - do not resuscitate). However, should the child's parents not agree to this decision, classification would still be A.

Class C: Discontinuance of life sustaining therapy.

Patients are assigned to this category whose continued survival is wholly dependent on highly sophisticated life support systems. Dying patients with negligible prospect of recovery and patients with brain death are usual instances of where this classification would be employed. However, should the child's parents not agree to this decision, classification would still be A or B.

It is the responsibility of the Attending Physician to note clearly in the chart the assignment of a child to Class B or C. Houseofficers do not have the authority to write a classification B or C note, although in emergency situations, if a child shows unexpected improvement, a houseofficer does have the authority to revoke orders not to resuscitate. The Attending Physician's classification note should give the base for the decision in some detail. The concurrence of the parents should also be noted.

The Chief of Pediatrics or the Directors of the Intensive Care Units should be informed as appropriate of all patients classified in Group C.

In cases where the Attending Physician is of the opinion that a decision made by the parents will adversely affect the interests of the child, the Chairman of the Department will be notified. If he concurs, recourse will be had to the courts.

Approved by the Board of Trustees at its meeting of
November 17, 1982

EXHIBIT 1

NONDISCRIMINATION GRIEVANCE PROCEDURE

It is the policy of YNHH to comply voluntarily with Section 504 of the Rehabilitation Act of 1973, Title VI of the Civil Rights Act of 1964, and HHS regulations pertaining thereto. The Yale-New Haven Hospital therefore has adopted this internal grievance procedure to provide prompt and equitable resolution of complaints alleging any claim of unlawful discrimination.

The following rules apply to complaints filed under this procedure:

1. A complaint shall be in writing, contain the name and address of the person filing it, and briefly describe the action alleged to be discriminatory.
2. A complaint shall be filed in the office of the Hospital's coordinator, Richard Burford, within a reasonable time after the person filing the complaint becomes aware of the action alleged to be discriminatory.
3. The Hospital shall conduct such investigation of a complaint as may be appropriate to determine its validity. These rules contemplate informal

but thorough investigations, affording all interested persons and their representatives, if any, an opportunity to submit evidence relevant to a complaint.

4. The Hospital shall issue a written decision determining the validity of the complaint no later than 30 days after its filing.

5. The Hospital shall maintain the files and records relating to complaints filed hereunder. Mr. Burford may assist persons with the preparation and filing of complaints, participate in the investigation of complaints, and advise the Hospital concerning their resolution.

6. The right of a person to prompt and equitable resolution of a complaint filed hereunder shall not be impaired by the person's pursuit of other remedies, and utilization of this grievance procedure is not a prerequisite to the pursuit of other remedies. A person may at any time file a complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, Room 2403, John F. Kennedy Federal Building, Boston, Massachusetts 02203, Tel. (617) 223-0247, TTY (617) 223-4000.

7. These rules shall be liberally construed to protect the substantial rights of interested persons and to assure compliance by the Hospital with Federal statutes and regulations prohibiting unlawful discrimination.

NONDISCRIMINATION NOTICE

It is the policy of Yale-New Haven Hospital to comply voluntarily with Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973, as amended, and the Age Discrimination Act of 1973, as amended, and the U. S. Department of Health and Human Services regulations (45 C.F.R. Parts 80, 84, and 91, respectively) pertaining thereto.

Yale-New Haven Hospital does not, on the basis of race, color, national origin, handicap, or age, unlawfully discriminate in admission or access to, or treatment or employment in, its programs or activities that receive Federal financial assistance.

For further information about this policy and Yale-New Haven Hospital's grievance procedure for resolution of complaints, contact Richard B. Burford, Assistant Administrator, 20 York Street, New Haven, Connecticut 06510, Telephone (203) 785-2600.

YALE-NEW HAVEN HOSPITAL (YNHH)

NONDISCRIMINATION PLAN

1. It is the policy of YNHH to comply voluntarily with Section 504 of the Rehabilitation Act of 1973, Title VI of the Civil Rights Act of 1964, and regulations of the U. S. Department of Health and Human Services pertaining thereto.

2. The grievance procedure attached as Exhibit 1 to this Plan will be furnished to each person who files, or inquires about filing, a complaint alleging any unlawful discrimination.

3. YNHH will continue to include nondiscrimination notices in its publications including employee handbooks, recruitment materials, public information booklets, etc.. These will be revised in the form annexed hereto. Such notices also shall be prominently posted and maintained in appropriate YNHH administrative offices and service locations and furnished to any unions or professional organizations engaged in bargaining or having contractual relationships with YNHH.

4. YNHH will provide appropriate auxiliary aids to hearing impaired persons where necessary to afford such persons an equal opportunity to benefit from the service in question. Currently, YNHH's auxiliary aids for the hearing impaired

include flash cards, use of paper, pencil and clipboard, telephone amplification devices, and sign language interpreters deemed qualified by the Connecticut Commission for the Deaf. YNHH will not require a patient to provide or pay for the services of a sign language interpreter. YNHH will continue to provide to its nursing and clerical staffs appropriate courses in basic sign language skills. YNHH will not rely on family members or friends of hearing impaired patients to serve as sign language interpreters except where a patient expressly requests such an arrangement. YNHH has installed a telecommunication device for the deaf (TTY) which is located at the Emergency Room control desk. All clerical staff members are trained in the use of the TTY and it is accessible 24 hours a day. YNHH will utilize sign language interpreters and its TTY, as appropriate, to provide effective notice to hearing impaired persons concerning benefits, services, waivers of rights, or consent to treatment.

5. YNHH will provide appropriate auxiliary aids to visually impaired persons where necessary to afford such persons an equal opportunity to benefit from the service in question. Currently, YNHH's auxiliary aids include the provision of readers at no cost to the patient. YNHH has a policy which allows guide dogs access to all areas of the hospital that are open to the general public and for employees

to use them in areas appropriate to perform their duties. YNHH is prepared to draw upon a full range of communication options (auxiliary aids) in order to ensure that visually impaired persons are provided with effective access to health care services. To this end, YNHH will develop the use of taped or braille materials where appropriate.

6. YNHH's Section 504 Coordinator and Patient Representative will be responsible for informing all staff in patient contact positions in regard to these policies and procedures and the availability of auxiliary aids.

Yale-New Haven Hospital

November 19, 1984
Date

John E. Fenn, MD
Its ~~President~~/Chief of Staff

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office for
Civil Rights

Region 1
Room 2403
John F. Kennedy Federal Bldg
Government Center
Boston, MA 02203

August 16, 1984

J. Michael Eisner, Esquire
Wiggin & Dana
Counsellors at Law
195 Church Street
P.O. Box 1832
New Haven, Connecticut 06508

Re: Compliance Review No. 01-82-7002

Dear Mr. ~~Eisner~~ Michael:

Pursuant to our recent telephone conversation, I am enclosing for your review and consideration a proposed "Compliance Plan" which would enable the Office for Civil Rights (OCR) to close the above-referenced review.

Please note that I am flexible as to the format of this Plan. For example, it may be labelled as "Voluntary Action Plan." Or, it may be in the form of a letter from President Smith, or Dr. Fenn, or from you as counselor for Yale-New Haven Hospital (YNHH), incorporating the substance of the Plan. In regards to the auxiliary aid areas, YNHH may already have most, if not all of the requirements in place; if so, you may rewrite or modify that section or attach YNHH documents.

Assuming we have general agreements on the substance of the Plan and OCR receives the written commitment from YNHH, we will issue a letter of compliance. This letter will contain the following elements: Specifically, we will find YNHH, at the time of the review, compliance with the following issues: patient admissions, room assignments and transfers, and the granting of staff privileges under Title VI. We will also find YNHH, by taking voluntary action, to be in compliance with the following issues: nondiscrimination notice under Title VI and Section 504, and grievance procedure and auxiliary aids under Section 504. The letter will state that the issue of handicapped infant is being addressed by Complaint No. 01-83-1001 and the courts have issued injunctions against OCR from making findings. The letter will also recommend that YNHH, in accordance with 45 C.F.R. §80.6(b), maintain racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in its federally assisted programs.

I hope that the above clarifications will be helpful and look forward to expeditiously resolving the outstanding issues of the compliance review. I am available to discuss the matter with you over the phone or at our meeting on September 18, 1984.

Thank you for your cooperation and assistance. Should you have any questions, please call me at (617) 223-0247.

Sincerely yours,

Peter

Peter K. Chan
Equal Opportunity Specialist
Office for Civil Rights
Region I

Enclosures

Yale-New Haven Hospital (YNHH)

Compliance Plan for YNHH under 45 C.F.R. §§84.7(b), 84.8 and 84.52 of the U.S. Department of Health and Human Services Regulation Implementing Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. §794).

1. The grievance procedure attached as Exhibit 1 to this Plan will be utilized to comply with 45 C.F.R. §84.7(b). YNHH shall, without cost, furnish a copy of the grievance procedure and a copy of 45 C.F.R. Part 84 to each person who files, or inquires about filing, a complaint alleging any action prohibited by the regulations.

2. The form of notice attached as Exhibit 2 to this Plan will be utilized to comply with 45 C.F.R. §84.8. The notice will be included in employee handbooks and training manuals, recruitment materials and other publications containing general information that YNHH makes available to the public, participants, beneficiaries, applicants or employees, including those with impaired vision or hearing. The conditions of the preceding sentence may be met either by including appropriate inserts in existing materials and publications or by revising and reprinting the materials and publications. The notice shall also be prominently posted and maintained in every YNHH administrative office and service location and furnished to any unions or professional organizations holding collective bargaining or professional agreements with YNHH.

3. In accordance with 45 C.F.R. §84.52(d), YNHH will provide appropriate auxiliary aids to hearing impaired persons where necessary to afford such persons an equal opportunity to benefit from the service in question. Currently, YNHH's auxiliary aids for the hearing impaired include flash cards, use of paper, pencil and clipboard, telephone amplication devices, and sign language interpreters deemed qualified by the Connecticut Commission for the Deaf. YNHH will not require a patient to provide or pay for the services of a sign language interpreter. YNHH will continue to provide to its nursing and clerical staff appropriate course in basic sign language skills. YNHH will not rely on family members or friends of hearing impaired patients to serve as sign language interpreters except where a patient expressly requests such an arrangement. YNHH has installed a telecommunication device for the deaf (TTY) which is located at the Emergency Room control desk. All clerical staff members are trained in the use of the TTY and it is accessible 24 hours a day. In accordance with 45 C.F.R. §84.52(b), YNHH will utilize sign language interpreters and its TTY, as appropriate, to provide effective notice concerning benefits, services, waivers of rights, or consent to treatment to hearing impaired persons.

4. In accordance with 45 C.F.R. §84.52(d), YNHH will provide appropriate auxiliary aids to visually impaired persons where necessary to afford such persons an equal opportunity to benefit from the service in question. Currently, YNHH's auxiliary aids include the provision of readers, at no cost to the patient. YNHH has a policy which allows guide dogs access to all areas of the hospital that are open to the general public and for employees to use them in areas appropriate to perform their duties.

YNHH is prepared to draw upon a full range of communication options (auxiliary aids) in order to ensure that visually impaired persons are provided with effective access to health-care services. To this end, YNHH will develop the use of taped or braille materials, where appropriate.

5. YNHH's Section 504 Coordinator and Patient Representative will be responsible for informing all staff in patient contact positions of these policies and procedures and the availability of auxiliary aids.

YNHH's submission of this Compliance Plan does not constitute an admission that its past policies or practices have violated Section 504 or 45 C.F.R. Part 84.

Yale-New Haven Hospital

Date

Its President/Chief of Staff

Exhibit 1

NONDISCRIMINATION GRIEVANCE PROCEDURE

The Yale-New Haven Hospital (name of recipient) has adopted this internal grievance procedure to provide prompt and equitable resolution of complaints alleging any action prohibited by the U.S. Department of Health and Human Services regulations implementing Federal statutes that prohibit discrimination on the basis of race, color, national origin, sex, handicap, age and religion, in programs and activities receiving Federal financial assistance, including, as applicable: 45 C.F.R. Part 80, implementing Title VI of the Civil Rights Act of 1964 (42 U.S.C. §2000d et seq.); 45 C.F.R. Part 83, implementing Sections 704 and 855 of the Public Health Service Act (42 U.S.C. §§292d and 298b-2); 45 C.F.R. Part 84, implementing Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. §794); 45 C.F.R. Part 86, implementing Title IX of the Education Amendments of 1972, as amended (20 U.S.C. §1681 et seq.); 45 C.F.R. Part 91, implementing the Age Discrimination Act of 1975, as amended (42 U.S.C. §6101 et seq.); and 45 C.F.R. Part 92, implementing block grant provisions of the Omnibus Budget Reconciliation Act of 1981 (42 U.S.C. §§300w-7, 300x-7, 300y-9, 708, 8625 and 9906. Copies of these statutes and regulations may be obtained from ______________________________, (name, title, office address and telephone number) who has been designated to coordinate the efforts of the Yale-New Haven Hospital (name of recipient) to comply with the regulations.

The following rules apply to complaints filed under this procedure:

1. A complaint should be writing, contain the name and address of the person filing it, and briefly describe the action alleged to be prohibited by the regulations.

2. A complaint should be filed in the office of the ____________________ (title of above-named coordinator) within a reasonable time after the person filing the complaint becomes aware of the action alleged to be prohibited by the regulations.

3. The ____________________ (title of recipient's chief executive officer) or his/her designee, shall conduct such investigation of a complaint as may be appropriate to determine its validity. These rules contemplate informal but thorough investigations, affording all interested persons and their representatives, if any, an opportunity to submit evidence relevant to a complaint.

4. The ____________________ (title of recipient's chief executive officer) shall issue a written decision determining the validity of the complaint no later than 30 days after its filing.

5. The ____________________ (title of above-named coordinator) shall maintain the files and records of the ____________________ (name of recipient) relating to complaints filed hereunder. The ____________________ (title of above-named coordinator) may assist persons with the preparation and filing of complaints, participate in the investigation of complaints, and advise the ____________________ (title of recipient's chief executive officer) concerning their resolution.

6. The right of a person to prompt and equitable resolution of a complaint filed hereunder shall not be impaired by the person's pursuit of other remedies, and utilization of this grievance procedure is not a prerequisite to the pursuit of other remedies. A person may at any time file a complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, Room 2403, John F. Kennedy Federal Building, Boston, Mass. 02203, Tel. (617) 223-0247, TTY (617) 223-4000.

7. These rules shall be liberally construed to protect the substantial rights of interested persons, to meet appropriate due process standards and to assure compliance by the ____________________ with Federal
(name of recipient)
statutes and regulations.

Exhibit 2

NONDISCRIMINATION NOTICE

In accordance with Title VI of the Civil Rights Act of 1964 (42 U.S.C. §2000d et seq.). Sections 704 and 855 of the Public Health Service Act (42 U.S.C. §§292d and 298b-2), Section 504 of the Rehabilitation Act of 1973. as amended (29 U.S.C. §794). Title IX of the Education Amendments of 1972, as amended (20 U.S.C. §1681 et seq.), the Age Discrimination Act of 1975, as amended (42 U.S.C. §6101 et seq.), and block grant provisions of the Omnibus Budget Reconciliation Act of 1981 (42 U.S.C. §§300w-7, 300x-7, 300y-9, 708, 8625 and 9906), the Yale-New Haven Hospital (name of recipient) does not discriminate on the basis of race, color, national origin, sex, handicap, age or religion in admission or access to, or treatment or employment in, its programs or activities. The person whose name appears below has been designated to coordinate the efforts of the Yale-New Haven Hospital (name of recipient) to comply with the U.S. Department of Health and Human Services regulations (45 C.F.R. Parts 80, 83, 84, 86, 91 and 92) implementing these Federal laws. For further information about the regulations and our grievance procedures for resolution of discrimination complaints, contact

____

(name and title of designated coordinator, office address and telephone number).

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office for
Civil Rights

Region 1
Room 2403
John F. Kennedy Federal Bldg.
Government Center
Boston, MA 02203

December 5, 1984

Mr. C. Thomas Smith
President
Yale-New Haven Hospital
New Haven, Connecticut 06504

Re: Compliance Review No. 01-82-7002

Dear Mr. Smith:

In 1982, the Office for Civil Rights (OCR) selected Yale-New Haven Hospital (YNHH) as one of four teaching hospitals for review regarding compliance with Title VI of the Civil Rights Act of 1964 (42 U.S.C. §2000d et seq.) and Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. §794), implemented by U.S. Department of Health and Human Services (HHS) regulations found at 45 C.F.R. Parts 80 and 84, respectively.

As a recipient of Federal financial assistance from HHS, YNHH is required to comply with these statutes and regulations. In addition, YNHH has also signed Assurances of Compliance with HHS under Title VI (Form 441) and Section 504 (Form 641).

Title VI prohibits discrimination against individuals on the basis of race, color, or national origin. The compliance review examined whether YNHH is in compliance with 45 C.F.R. §§80.3(b), 80.5(e), and 80.6(d) with respect to the following issues:

- patient admissions
- patient room assignments and transfers
- granting of staff privileges, and
- the adoption and dissemination of a nondiscrimination policy and notice.

Section 504 prohibits discrimination against qualified handicapped persons in the provision of services and employment. The compliance review examined whether YNHH has met the following procedural requirements:

- adoption and dissemination of a nondiscrimination policy and notice (45 C.F.R. §84.8)
- designation of a Section 504 coordinator (45 C.F.R. §84.7(a)), and

- adoption and dissemination of grievance procedures (45 C.F.R. §84.7(b)).

OCR also examined whether YNHH has implemented policies and procedures regarding the effective communication with, and the provision of auxiliary aids to, hearing and visually impaired persons (45 C.F.R. §84.52).

At the time of the on-site review in 1982, OCR found that:

- YNHH's policies and procedures regarding patient admissions, room assignments and transfers, and the granting of staff privileges were in compliance with Title VI. Contacts with community and advocacy groups did not disclose any allegations of violations; and

- YNHH had designated a Section 504 coordinator pursuant to 45 C.F.R. §84.7(a).

OCR also found that:

- YNHH had not provided or disseminated notice of its nondiscrimination policy pursuant to Title VI and Section 504 requirements;

- YNHH did not have a grievance procedure that meets the requirement of 45 C.F.R. §84.7(b); and

- Although YNHH had installed a TTY in its Emergency Room and has made arrangements for the use of qualified sign language interpreters, there was a lack of specific policies or procedures regarding effective communication with and the provision of auxiliary aids to hearing or visually impaired persons.

Since the on-site, YNHH has taken voluntary actions to resolve the identified deficiencies. Productive negotiation between OCR and YNHH has culminated in a Nondiscrimination Plan signed by John E. Fenn, M.D., Chief of Staff, dated November 19, 1984.

The Plan commits YNHH to utilize and disseminate a nondiscrimination notice and grievance procedure acceptable under the HHS regulations. In the area of effective communication with and auxiliary aids to visually and hearing impaired persons, YNHH will continue to draw upon a full range of communication options to ensure that these persons are provided with effective access to health care services. These include 24 hour access to the TTY, use of sign language interpreters deemed qualified by the Connecticut Commission for the Deaf, training of staff in basic sign language skills and the use of TTY, provision of readers, and the development of tapes or braille materials where appropriate. In addition, YNHH's Section 504 Coordinator and Patient Representative will be responsible for informing all staff in patient contact positions in regard to these policies and procedures and the availability of auxiliary aids.

With our acceptance of the Plan, OCR now determines YNHH to be in compliance with Title VI and Section 504 with respect to those issues specifically examined in the compliance review.

45 C.F.R. §80.6(b) Requirement

During the review, YNHH's inability to provide OCR with readily retrievable racial/ethnic data prevented OCR from making statistical comparisons. We therefore wish to notify you of the requirement, in accordance with 45 C.F.R. §80.6(b), to maintain racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in federally assisted programs. YNHH should take immediate action to collect racial/ethnic information with respect to its patients, clients, participants, employees, and applicants for staff privileges.

The following five categories should be used for identification and collection purposes:

> Black, not of Hispanic Origin. A person having origin in any of the black racial groups of Africa.
>
> Hispanic. A person of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race.
>
> Asian or Pacific Islander. A person having origins in any of the original people of the Far East, Southeast Asia, the Indian Subcontinent, or the Pacific Islands. This area includes, for example, China, Japan, Korea, the Philippine Islands, and Samoa.
>
> American Indian or Alaska Native. A person having origins in any of the original people of North America, and who maitains cultural identification through tribal affiliation or community recognition.
>
> White, not of Hispanic Origin. A person having origins in any of the original people of Europe, North Africa, or the Middle East.

Handicapped Infant Issue

As part of the review, OCR conducted factfinding at YNHH to determine if handicapped infants were being discriminated against in the provision of treatment or services. After the compliance review was begun, OCR received a separate complaint against YNHH alleging noncompliance with Section 504 in the treatment and care of handicapped infants. Because of the complaint, OCR conducted additional factfinding in this area.

Decisions from the United States Court of Appeals for the Second Circuit have barred HHS from applying Section 504 and the implementing regulations to health care for handicapped infants. OCR will address this issue when this bar is removed.

Under the provisions of the Freedom of Information Act, as amended, 5 U.S.C. §552, and its pertinent regulation, 45 C.F.R. Part 5, the contents of this letter and/or other information received during the review/investigation may be released upon request from the public. However, if such a request is made, we will maintain the confidentiality of information that, if released, would constitute an unwarranted invasion of privacy.

OCR greatly appreciates your cooperation and the assistance extended by your staff to our investigators. We would like to especially thank Dr. John E. Fenn, Chief of Staff; J. Michael Eisner, Legal Counsel; Edward Dowling, Vice President of Human Resources; Virginia Roddey and Angela Holder of the Risk Management/Medical Legal Office.

Should you have any questions, please contact Mr. Peter K. Chan of my staff at (617) 223-0247.

Sincerely yours,

Caroline J Chang

Caroline J. Chang
Regional Manager
Office for Civil Rights
Region I

cc: Dr. John E. Fenn, Chief of Staff
✓J. Michael Eisner, Esq.

oth Oklahoma Teaching Hospitals 800 Northeast 13th PO Box 26307 Oklahoma City, OK 73126

November 7, 1988

William J. Howard
General Counsel
United States Commission on Civil Rights
1121 Vermont Ave. N.W.
Washington, D.C. 20425

RE: Commission Report on Medical Treatment of Handicapped Infants

Dear Mr. Howard:

My office is in receipt of the second set of revised excerpts to your forthcoming report relating to medical treatment of handicapped infants. You have invited a response to such excerpts without the benefit of any contextual information which may indicate the manner in which such excerpts will be used. The objections raised below relate not only to the abusive substantive material of your report, but also to the gross inadequacy and insufficiency of your investigation process. Such procedural objections are part and parcel of this response and shall not be carved out by your editing from the below material relating to this issue as we receive our due process in the appendix of your "Report". We find it abhorrent that your Commission, as a governmental entity, could be so deficient in it's duty to investigate and protect the civil and constitutional rights of all parties. We believe it is a fundamental defect undermining your report that neither the Department of Human Services or Children's Hospital of Oklahoma (formerly known as Oklahoma Children's Memorial Hospital) have ever received any requests or contact by your Commission regarding any of the practices, issues, etc. discussed in your excerpts. This is incredible considering the fact that you first held hearings on this issue in June of 1985, yet the first notice this hospital has received is an opportunity to respond to draft excerpts of your report. (We have been advised that Dr. Gross was invited to testify, but only after a lawsuit regarding this situation had been filed.) It is more incredible upon noting the drastic changes which have taken place in excerpts received one month apart (September 14th and October 19th, 1988). Therefore, and assuming the attached revisions to be final, we have several observations to make.

1. REPORT AUTHORITY. For interpretative authority, the report repeatedly relies upon apparent law review articles written by Sharon Paulus and Martin Gerry in "Issues of Law and Medicine".

A component of the Department of Human Services and affiliated with the University of Oklahoma Health Sciences Center

However, you fail to note that both Ms. Paulus and Mr. Gerry are attorneys of record of plaintiffs in the lawsuit against Children's Hospital of Oklahoma. Furthermore, the journal "Issues in Law and Medicine" is the self-serving creation of the National Legal Center for the Medically Dependent and Disabled, Inc., - a plaintiff in the lawsuit. When has your office reviewed the court records or the medical records of Carlton Johnson?

2. THE FORMULA. In the new excerpt beginning "OKLAHOMA CASE", your reference of information (footnote #1) is the Paulus article. In your second paragraph, you state:

> In this evaluation, the [meningomyelocele] team members wrote, they were "influenced" by a quality of life formula: QL=NE x (H+S).

This a clever but deceitful statement. Your implication that the quality of life formula was used in the evaluation of children is a distortion of what is stated in the article and otherwise totally denied. The repeated assertion by the disability groups and now your Commission that a "quality of life formula" served as a basis for denying treatment is an unadulterated lie. The original statement by Robert Fulton and Antonio Padilla on behalf of the Oklahoma Department of Human Services and Children's Hospital emphasizes the formula's non-use, which has also been publicly refuted by Dr. Gross. Furthermore, the assertion that a quality of life formula was used as a basis for determining treatment has been unequivocally refuted by the meningomyelocele team and clinic staff as noted in the attached affidavit (See attachment, orginally attached to Fulton and Padilla statement, May 23, 1985.). The formula was simply used as an illustration device and was not even discovered by Dr. Gross until 1981 when he was writing the paper. After describing the formula you continue your excerpt with "based on the assessment, the team recommended to the parents the infant be given either vigorous or supportive care". This continued representation that the team made a recommendation based upon an assessment which included the formula is simply irresponsible. The article clearly states the criteria that were used to evaluate these newborn and it doesn't include such formula.

Along the same line, you later state:

> The team members acknowledged that "treatment for babies with identical [degree of mental and physical disability] could be quite different, depending on the contribution from home and society".

This statement is made with the discussion of the formula and did not relate to the management by the team.

3. CARLTON JOHNSON. The Department and Hospital will not discuss treatment of individuals, including Carlton Johnson, who

continues to be treated at the hospital clinic. Suffice it to say, that you have relied upon the Paulus article which has quoted a journalist, who has quoted the plaintiff, etc.

4. DENIAL OF TREATMENT. This excerpt states:

> There have been isolated instances in which denial of treatment was publicly announced in medical journal articles, most notably those reporting decisions to withhold lifesaving treatment from a number of newborn children with disabilities at * * * and similar decisions at Oklahoma Children's Memorial Hospital in the 1980's. 1/ In those cases the physician's involved were deliberately crusading for open acceptance of denial of treatment practices by their fellow professionals.

It is absolutely inaccurate to state that treatment was denied any infant by the physicians or hospital at Children's Hospital of Oklahoma. As Dr. Gross made very plain in his article, the decision was made by the parents after full disclosure of the child's condition and treatment option by the physicians.

5. ECONOMIC DISCRIMINATION. In your excerpt from "Chapter 12", wherein you attempt to summarize the article written by Gross et al, you state:

> "In addition the criteria used by the team included an assessment of 'contibution from home and family' so that those families who had greater resources might receive a recommendation for treatment and those families with fewer resources would be more likely to receive a recommendation against it, even though the severity of the disability might be the same in both cases."

This is a reckless distortion of the discussion by Dr. Gross of the formula. Nowhere in the article is there any indication that higher income families received treatment and poorer families did not. In the article's discussion of the Shurtleff criteria (which were relied upon), criteria (6) states "a family with economic and intellectual resources who lived within reach of an appropriate medical facility, or a commitment by a social agency to provide needed resources such as foster home or medical care costs". The actual resource/reimbursement facts are as follows:

1. 100% of patients on public assistance without insurance were aggressively treated.

2. 69% of patients qualifying for medical assistance (medicaid or state crippled children's program) were aggressively treated.

3. 58% of the patients with private insurance, including Champus were aggressively treated.

4. 50% of persons with private insurance but who also qualify for medical assistance were aggressively treated.

These statistics clearly belie your unfounded accusations and generalizations.

6. REPORT BIAS. Throughout the excerpt titled "Chapter 12", the author's bias is repeatedly displayed. For example:

A. The article does not describe an "experiment", but is a retrospective case review.

B. In describing the process used by the hospital team on page 1, you state "For those infants born with high lesions and who were suspected of having hydrocephalus or other anomalies a formal meeting was convened to make a treatment recommendation to the family." (Emphasis added.) The use of the word "suspected" is an inflammatory addition which is in complete variance with the radiography and CT scans described in the evaluation.

C. To describe the sac as the size of a "basketball" is outrageous. You have the CNN video tape, look at it.

D. It is a distortion to state the "families of five children 'demanded' treatment" when it was simply the option they chose after presentation of the child's condition.

E. Likewise, "at the end of the 'experiment' twenty four families had 'finally agreed' to the non-treatment regimen..." reflects your editorial bias.

7. SURGEON GENERAL C. EVERETT KOOP. The excerpt states:

> *** Subsequent to May 30, 1984, Surgeon General C. Everett Koop was to make 'an indirect approach to the University of Oklahoma *** to see what current practices are being utilized by the University of Oklahoma in their determinations of who should be treated'. 13/ Physicians at the hospital refused to give the Surgeon General assurances that the practices had ceased. 14/

In the "Background Information" attached to the statement by Robert Fulton and Antonio Padilla of May 23, 1985, this issue was thoroughly explained as follows:

> Involvement of U. S. Surgeon General Koop
>
> When the attorneys who authored the May 8, 1985, letter were asked by the news media whether they had contacted officials at DHS or OCMH prior to making their allegations, they reportedly stated that OCMH had continuously rebuffed attempts by C. Everett Koop, Surgeon General of the U.S.

> Public Health Service, to clarify OCMH's current position on this subject. To date, neither the Hospital nor the Department of Human Services have been contacted by the Surgeon General.
>
> We do understand that Surgeon General Koop spoke informally on two occasions with an acquaintance at OCMH, Dr. E. Ide Smith, Chief of Pediatric Surgery -- once during a telephone conversation last summer [1984] and once during an incidental meeting at a medical conference in the fall. (See attached affidavit.) On both occasions, Dr. Smith assured Koop of complete compliance by OCMH with the federal regulations and repudiated any allegation that OCMH physicians used a selection formula to determine the type of treatment given to the newborn. Dr. Koop suggested to Smith that OCMH should clear the air with disability groups regarding its policies and Smith related the information to the OTH administration. At Dr. Koop's request, Dr. Smith relayed this information as coming from "good authority". (It should be noted that Fulton had by this time extended his invitation to Mr. Gerry.) [Martin H. Gerry, co-counsel for the National Legal Center for the Medically Dependent and Disabled, Inc.]
>
> These contacts were never considered by Dr. Smith or OCMH to be more than friendly advice and certainly were never considered as formal requests for clarification of OCMH policies. Had Surgeon General Koop made such a request, DHS and OCMH would have been eager to provide him with information and assurances with respect to treatment of children. To extrapolate from casual conversations between professional colleagues that OCMH has "rebuffed" requests by the Surgeon General to clarify OCMH's position is unfair to Surgeon General Koop as well as the Hospital.
>
> While Surgeon General Koop had informal contact with a member of the medical staff at OCMH, the authors of the May 8th letter and their clients made absolutely no effort to obtain information on OCMH policy or practice. Dr. Koop's informal contacts do not excuse their failure to make inquiry at OCMH, especially in light of the invitation extended to Martin Gerry. If they didn't want to bother with coming to Oklahoma, they could have a least written or called. Morever, DHS and OCMH's policies on this subject are a matter of public record which could have been procured and reviewed by local counsel, Mr. Fairbanks, with a minimum of effort.

As indicated by the above statement issued in 1985, with the accompanying affidavit of Dr. Smith, your conclusion suffers from the inexcusable lack of inquiry and investigation by your office. Dr. Smith, one of many hospital service chiefs, was an acquaintance of the Surgeon General and could hardly be labeled a "hospital official" by virtue of his service position.

Obviously, no further communication was required with his acquaintance since appropriate assurances were provided.

8. LAWSUIT AND INVESTIGATION. The excerpt states:

> *** In October, 1985, the American Civil Liberties Union and the National Center for the Medically Dependent and Disabled (a Legal Services Corporation funded National Support Center) filed suit against a number of physicians at Oklahoma Children's Memorial Hospital on behalf of Sharon Johnson (Carlton Johnsons's mother), Carlton Johnson himself, the parents of another child with disabilities who had died after alledgedly being denied lifesaving treatment at Oklahoma Children's Memorial Hospital, the Spina Bifida Association of America, and the Association for Persons with Severe Handicaps. 15/

The Director of this Department, Robert Fulton (also a former secretary of welfare at HEW) personally invited Martin H. Gerry, an attorney for the National Legal Center for the Medically Dependent to investigate with medical experts in the summer of 1984. No response or even the slightest inquiry was received by Mr. Gerry, the so-called National Legal Center, or the ACLU until James Bopp, Jr., acting on behalf of the National Legal Center held his well-staged press conference in a U.S. Senate office building which demanded the department and hospital submit to a consent order or otherwise face a class action lawsuit. There was no independent investigation but across the street from the press conference was the United States Supreme Court which was then deciding whether or not to grant certiorari on the "Stoneybrook Case" which later resulted in the Bowen decision. Incidentally, more than half of the lawsuit has been dismissed with very little discovery accomplished.

In conclusion, it is difficult for the agency and hospital to place much credence in your report based upon the above reasons. Thank you for this opportunity to respond.

Very truly yours,

Charles L. Waters
General Counsel

Frederick B. Aurin, Jr.
Asst. General Counsel

ATTESTATION

STATE OF OKLAHOMA)
) ss:
COUNTY OF OKLAHOMA)

I, Frederick B. Aurin, Jr., of lawful age, being first duly sworn upon oath, state:

That the foregoing letter is written on behalf of the Department of Human Services and Children's Hospital of Oklahoma (formerly Oklahoma Children's Memorial Hospital) and in my capacity as Assistant General Counsel.

Frederick B. Aurin, Jr.
OBA# 379
Assistant General Counsel
Department of Human Services

Subscribed and sworn to before me this 7th day of November, 1988.

Barbara McCurdy
Notary Public

My Commission Expires:
10-8-89

State of Oklahoma
Department of Human Services

Sequoyah Memorial Office Building
P.O. Box 25352
Oklahoma City, Oklahoma 73125

COMMISSION
FOR HUMAN SERVICES

ROBERT FULTON
Director of Human Services

May 23, 1985

Thomas J. Marzen
National Legal Center
for the Medically Dependent
and Disabled, Inc.
P. O. Box 441069
Indianapolis, Indiana 46204

Dear Mr. Marzen:

This is in response to the letter of May 8, 1985, to the undersigned and several other individual addressees from your organization regarding a potential lawsuit. Your letter relates to compliance by Oklahoma Children's Memorial Hospital (OCMH) with Constitutional and statutory requirements pertaining to the handicapped.

The presentation of your concerns before a national news conference two days before our receipt of your letter and without the courtesy of giving us an opportunity to respond was unorthodox and unprofessional.

Several months ago, Robert Fulton, Director of the Oklahoma Department of Human Services (DHS) and one of the addressees of your May 8th letter, personally invited Mr. Martin H. Gerry, one of your co-counsel, to visit OCMH, bringing whatever medical or legal experts he cared to bring. Mr. Fulton assured Mr. Gerry that the visitors would be allowed to interview physicians and administrators, observe procedures and ask any questions they thought relevant to the care of severely handicapped infants. Unfortunately, you never responded.

In view of your behavior, it is clear that your organization is more interested in publicity than truth. It is sad that you have gained this publicity by vilifying OCMH — one of the finest child care institutions in this nation.

The litigation you are threatening is misguided and inappropriate. No children are "threatened" with lack of care or with improper treatment at OCMH. Children are not being "allowed to die" as alleged in your letter nor have the hospital or physicians engaged in human experimentation. "Quality of Life" or "contributions" anticipated from home, family and/or society are not considered in determining the type of treatment to provide to severely handicapped infants. An affidavit to this effect signed by current staff of the Myelomeningocele Clinic at OCMH and by hospital administrators is enclosed.

As explained in the enclosed background paper, OCMH is in full compliance with all federal and state laws on the matter of care of severely handicapped infants. In addition, OCMH established over a year ago an Infant Care Review Committee composed of physicians, nurses, attorneys and representatives of the lay community. The committee reviews medical treatment of newborns on a prospective and retrospective basis for the very purpose of assuring that medical treatment is provided for all infants regardless of handicap or anticipated physical or mental impairments. OCMH is in complete compliance with all of the so called "Baby Doe" requirements.

OCMH, like many other institutions caring for children with spina bifida, is today achieving a much higher survival rate for such children, as compared with the experience of only a few years ago because of increased knowledge and medical advances. Specifically, 25 newborn children with spina bifida have been treated at OCMH since January 1, 1983. Of the 25, 3 died within a very short time after birth of massive complications accompanying spina bifida. Since January of 1984, all 12 infants born with spina bifida and treated at OCMH have survived. The hospital has been able to accomplish these excellent results through the use of surgery and other intensive therapies.

We cannot, of course, agree to the proposed consent judgment forwarded with your May 8th letter. The proposed agreement would have us confirm allegations that are simply not true. Such an agreement is not appropriate. Children treated at OCMH are safe; indeed, those children with birth defects who are born at OCMH or referred there from elsewhere receive care equivalent to that available in other prominent medical institutions throughout the nation.

We do, however, renew the invitation extended earlier that you send a team of medical and legal experts to review current policies and procedures and interview physicians with respect to care and treatment of severely handicapped infants at OCMH. We believe it would be appropriate that experts chosen by you be joined by a few equally expert individuals chosen by us so that there will be maximum confidence that a thorough, unbiased and conclusive review is completed.

The enclosed background paper sets forth relevant information and comments on allegations contained in your letter of May 8th and the proposed consent agreement you transmitted.

Your public vilification of OCMH when it in fact has complied fully with the law and established medical standards is irresponsible. There can be little doubt that the trust and confidence that patients and their families have placed in the hospital have been jeopardized by your defamatory statements. You can be certain that your conduct has contributed to the grief and suffering of families already seriously overburdened by the tragedy of spina bifida.

We shall await with interest further communications from you, your associates and your clients. Please contact Roger Stuart, Assistant General Counsel for the Oklahoma Department of Human Services, if you need additional information or wish to convey information to us.

Sincerely,

Reginald D. Barnes

Reginald Barnes, Chairman
Oklahoma Commission for Human Services

Robert Fulton

Robert Fulton, Director
Department of Human Services

Antonio Padilla, Chief Executive
Officer, Oklahoma Teaching Hospitals

Donald F. Doenitz

Donald Doenitz, Administrator
Oklahoma Children's Memorial Hospital

Owen Rennert

Owen Rennert, M.D., Chief of Staff
Oklahoma Children's Memorial Hospital

Additional Background Information and Responses to Allegations Regarding Care of Children with Spina Bifida at Oklahoma Children's Memorial Hospital

Evolution of Federal and State Legislation and Regulations

Legal issues relating to the medical treatment of children born with severe deformities and disabilities have only recently been addressed by the courts and legislators. Not until this past year has Congress acted decisively to address the issues of the so-called "Baby Doe" situation. However, before the recent federal legislation was enacted the Oklahoma Department of Human Services (DHS), Oklahoma Teaching Hospitals (OTH) and Oklahoma Children's Memorial Hospital (OCMH) were in full compliance with regulations promulgated by the Federal Department of Health and Human Services in January, 1984. Despite the fact that those regulations have been held invalid by federal court action, OCMH has continued to strictly conform to their letter and spirit.

The first federal regulatory involvement in this issue began when the United States Department of Health and Human Services issued a notice on May 18, 1982, which informed affected parties of that Department's view that Section 504 of the Rehabilitation Act of 1973 applied to the medical care of handicapped infants. This was followed by the publication of "Interim Final Rules" on March 7, 1983, which required health care providers receiving federal financial assistance to post notices throughout their institutions and to create infant care review committees. Before compliance could be achieved, the Interim Final Rules were declared invalid on April 14th, 1983, in the case of the American Academy of Pediatrics vs. Heckler 561 F. Supp. 394 (D.D.C. 1983).

Subsequently, revised federal rules were initiated in January of 1984. The Oklahoma Department of Human Services and Oklahoma Children's Memorial Hospital immediately implemented the requirements and recommendations for voluntary action which accompanied the rules. On February 9, 1984, the Infant Care Review Committee of Oklahoma Children's Memorial Hospital, a voluntary committee, began operating in the spirit of the new rules.

The January, 1984, rules were set aside on February 23, 1984, by the Federal Court of Appeals, in U.S. v. University Hospital, State University of New York at Stoneybrook, 729 F.2d 144 (2nd Cir. 1984). In spite of that decision, on March 27th, 1984, the Oklahoma Human Services Commission, the governing body of the Department of Human Services and Oklahoma Children's Memorial Hospital, approved an amendment to the Department's child protective services procedures providing for investigation of any purported denials of treatment of children in hospitals anywhere in the state. On the same date, the Commission gave initial approval to a statement of purposes and operating procedures for the OCMH Infant Care Review Committee.

Moreover, Oklahoma's legislature took two separate actions in this area during 1984. House Bill 1133, enacted into law on April 10, 1984, added denial of needed medical treatment to the definition of child neglect contained in Oklahoma's statutes. In addition, the appropriations bill for DHS for FY-1985 (House Bill 1522), contained a provision directing the Commission for Human Services to implement policies and procedures providing added assurance that handicapped children receive proper treatment at OCMH. DHS supported both of these measures.

Thus, in spite of the Second Circuit's decision repudiating the January, 1984, federal regulations, Oklahoma chose to honor the letter and spirit of those rules. As the attachments indicate, these actions are a matter of public record.

The January, 1984, federal rules, and the federal statute enacted in October, 1984 (Public Law 98-457) were the result of a consensus reached by medical organizations and disability groups some of which are now represented by the authors of the May 8, 1985, letter. These attorneys and their clients have totally and irresponsibly failed to review what Oklahoma and its agencies have done. Moreover, their action has been launched despite the personal invitation to make an on-site review of OCMH and of spina bifida patients extended to Martin H. Gerry, Co-counsel for the plaintiffs, by the Director of the Oklahoma Department of Human Services, Robert Fulton. (This invitation is further dicussed in the cover letter.) Instead the attorneys and their clients have decided to proceed in a manner which defames the State of Oklahoma and the dedicated physicians and staff at OCMH. This grandstanding has ignored Oklahoma's good faith compliance with proposed federal statutes and regulations.

In addition, while the Courts have uniformly rejected any connections between Section 504 of the Rehabilitation Act of 1973 and the treatment of handicapped infants, the May 8th letter maintains that the State of Oklahoma is violating that statute. This is simply not the case.

Federal District Judge Gerhard Gesell in the American Academy of Pediatrics case threw out the original federal regulations as "arbitrary and capricious" and stated in his opinion that the rules failed to consider many highly relevant factors on "one of the most difficult and sensitive medical problems facing our society". Judge Gesell further pointed out:

> Traditionally, the difficult decision of when to withhold life-sustaining treatment of a defective newborn has been one within the privacy of the physician-patient relationship, without interference by State or Federal authorities.

Yet, the May 8, 1985, letter attempts to revive rules which were twice found invalid by Federal Courts and apply them retroactively to the 1977 to 1982 period.

Congress acted decisively with respect to the right to care of the handicapped in Public Law 98-457 (enacted October 9, 1984) and implementing regulations made final on April 15, 1985. The Department of Human Services has now responded with diligence to insure compliance with yet another set of regulations. However, as indicated, Oklahoma's compliance with stricter standards was achieved long before the federal statute was enacted and the implementing rules became final, and more than a year before the May 8, 1985, grandstand press conference in Washington, D.C..

OCMH Experience in Treating Newborn Children with Spina Bifida

To support allegations contained in the May 8, 1985, letter, numerous references are made to an article written by Dr. Richard Gross, a former faculty member of the University of Oklahoma, which was published in the October, 1983, issue of "Pediatrics" journal. In this article Dr. Gross retrospectively describes the experiences he and his associates had with children born with spina bifida from 1977 to 1982. The authors of the May 8th letter attempt to distort Dr. Gross' article by alleging that he selected treatment for patients through the use of a formula and that such a practice also represents past and present hospital policies. Those allegations are simply not true.

It is important to put Dr. Gross' article in a proper perspective. The article did not report on an "experiment", a research study nor a hospital policy. Rather, the article simply reported retrospectively on data collected between 1977 and 1982 on the treatment of newborn children with spina bifida.

The birth of a child with multiple congenital anomalies, with or without a poor prognosis for survival, is obviously a traumatic event for the family. The early and continuous treatment and care of such children evokes, for society as a whole, medical, philosophical, ethical and theological considerations. Although the problem of birth defects is not new, dramatic advances in neonatal care make it possible to sustain life in infants who would have died only a few years ago. At the heart of this matter is, as Judge Gesell noted, "one of the most difficult and sensitive problems facing our society — the question of what sort of life-sustaining treatment, if any, should be utilized to preserve the lives of severely mentally or physically defective infants".

The general approach to physician - family interaction described in Dr. Gross' article is common with many types of serious health care problems. Members of a team of health care professionals worked closely with each other in diagnosing patients' conditions and in presenting medical information to the families of children with spina bifida in order that the families could decide the nature and extent of medical intervention. This same approach was recently described in an article written by physicians at Children's Hospital of Philadelphia and reported in "Pediatrics" journal in January of this year. Those physicians describe a team similar to the one at OCMH which advised parents with respect to the likely result of surgical intervention so that they could make informed decisions with respect to their children. The fact that this method apparently represents that Hospital's present approach, while OCMH currently utilizes a review procedure endorsed by the very organizations attacking OCMH, makes threats of a lawsuit even more puzzling.

In any event, while it is not appropriate for OCMH to speak for Dr. Gross, he was recently contacted in order to discuss issues raised with respect to the October, 1983, article. Two significant facts emerged from the conversation. First, none of the attorneys nor their clients have ever spoken with or attempted to contact Dr. Gross to review with him their allegations and assumptions. Second, had they done so, they would have been assured that the so-called "quality of life" formula was never a part of the team's approach. Indeed, Dr. Gross stated that he was unaware of the formula until he began writing his paper. While he included the formula in the article for illustrative purposes, it was never applied to children within his care.

Moreover, the entire thrust of the approach Dr. Gross described was to allow parents to make informed decisions with respect to medical treatment. As in any other medical situation, it was necessary to relate to the parents the known disabilities and prospects of life for the children with and without surgical intervention. Therefore, to the extent that factors such as hydrocephalus, retardation, loss of bladder and bowel function, ambulation, and general survival prognosis were involved, parents were given such facts for the sole purpose of allowing them to make informed decisions regarding treatment.

The on going medical and societal debate in this country regarding the extent of parental rights on this sensitive issue have not yet been resolved. During the period dealt with in Dr. Gross' article, and in fact since the onset of modern medicine, decisions with regard to life-sustaining treatment of a child with multiple birth defects were made within the privacy of the physician-patient relationship. The approach described by Dr. Gross was representative of practices across the nation. Only recently has the government attempted to establish regulations which would govern decisions which were traditionally left to the family with advice from physicians and often clergy.

Finally, the 1977-1982 approach was not an "experiment". Neither the Hospital nor physicians have in the past or present performed experiments on these children. To that end, federal and state regulations regarding experimentation have always been rigorously followed at OCMH.

Alleged Racial Discrimination

The May 8th letter asserts that treatment provided by Dr. Gross and his colleagues was racially motivated and had the net result of discriminating against Blacks and "Indians". Apparently this allegation is based upon the assumption that, if the quality of life formula were used in making medical judgments, it would militate against medical treatment for minorities. As already noted, the quality of life formula referred to by Dr. Gross was never applied to his patients.

However, since it was specifically asserted that Blacks and "Indians" were discriminated against, a review has been made of the racial composition of the children with spina bifida referred to in Dr. Gross' paper. The racial composition of those receiving immediate surgical intervention, shunts and other aggressive therapies is as follows:

Black	White	Hispanic	Native American
100%	57%	83%	55%

These findings hardly support the assertion that Dr. Gross and his associates engaged in racial discrimination. Indeed, Dr. Gross' article does not indicate that race was ever a criterion. It appears that injection of the allegation of racial discrimination was only an attempt to inflame emotions, interest the media and discredit OCMH.

The Provision of Medical Treatment after Hospitalization

The implication that children with spina bifida are or have been placed in interim care facilities where antibiotics for active infection were purposefully withheld is incorrect. The Children's Shelter referenced in

Dr. Gross' article was a private facility which ceased operation in January, 1984. The placement of children at that facility was a decision made by a parent when home care was not possible. According to the former Medical Director of Children's Shelter, neither the Hospital nor physicians directed that antibiotics to control active infections be withheld. Indeed, children were supplied antibiotics and when illness presented itself, they were taken to OCMH for appropriate treatment. With respect to sedatives, the use of such medications for spina bifida patients has been highly criticized in the medical literature because of problems in their use in European countries. While sedatives were not normally given in these cases, analgesics were used for the control of pain according to the former Medical Director of Children's Shelter.

Involvement of U.S. Surgeon General Koop

When the attorneys who authored the May 8, 1985, letter were asked by the news media whether they had contacted officials at DHS or OCMH prior to making their allegations, they reportedly stated that OCMH had continuously rebuffed attempts by C. Everett Koop, Surgeon General of the U.S. Public Health Service, to clarify OCMH's current positon on this subject. To date, neither the Hospital nor the Department of Human Services have been contacted by the Surgeon General.

We do understand that Surgeon General Koop spoke informally on two occasions with an acquaintance at OCMH, Dr. E. Ide Smith, Chief of Pediatric Surgery — once during a telephone conversation last summer and once during an incidental meeting at a medical conference in the fall. (See attached affidavit) On both occasions, Dr. Smith assured Koop of complete compliance by OCMH with the federal regulations and repudiated any allegation that OCMH physicians used a selection formula to determine the type of treatment given to the newborn. Dr. Koop suggested to Smith that OCMH should clear the air with disability groups regarding its policies and Smith related the information to the OTH administration. At Dr. Koop's request, Dr. Smith relayed this information as coming from "good authority". (It should be noted that Fulton had by this time extended his invitation to Mr. Gerry.)

These contacts were never considered by Dr. Smith or OCMH to be more than friendly advice and certainly were never considered as formal requests for clarification of OCMH policies. Had Surgeon General Koop made such a request, DHS and OCMH would have been eager to provide him with information and assurances with respect to treatment of children. To extrapolate from casual conversations between professional colleagues that OCMH has "rebuffed" requests by the Surgeon General to clarify OCMH's position is unfair to Surgeon General Koop as well as the Hospital.

While Surgeon General Koop had informal contact with a member of the medical staff at OCMH, the authors of the May 8th letter and their clients made absolutely no effort to obtain information on OCMH policy or practice. Dr. Koop's informal contacts do not excuse their failure to make inquiry at OCMH, especially in light of the invitation extended to Martin Gerry. If they didn't want to bother with coming to Oklahoma, they could have at least written or called. Morever, DHS and OCMH's policies on this subject are a matter of public record which could have been procured and reviewed by local counsel, Mr. Fairbanks, with a minimum of effort.

As indicated in the cover letter, DHS and OCMH are quite prepared to undergo a full review by outside experts.

AFFIDAVIT

STATE OF OKLAHOMA)
)ss.
COUNTY OF OKLAHOMA)

I, E. Ide Smith, M.D., the undersigned, do state and affirm that during 2 recent conversations with C. Everett Koop, M.D., the Surgeon General of the United States, I advised Dr. Koop that Oklahoma Children's Memorial Hospital was in compliance with the Federal Baby Doe regulations with an active Infant Care Review Committee. I further advised Dr. Koop that there was no practice in which newborn handicapped children were selected for a particular treatment by use of a quality of life formula or any other non-medical considerations. Our conversations took place, first by phone during the summer of 1984 and, second, during an incidental meeting at a medical conference in Chicago in the fall of 1984.

E. Ide Smith

E. Ide Smith, M.D.
Chief of Pediatric Surgery
Oklahoma Children's Memorial Hospital

Signed and sworn before me this 22nd day of May, 1985.

______________________, NOTARY PUBLIC
My commission expires April 5, 1986

AFFIDAVIT

STATE OF OKLAHOMA)
)ss,
COUNTY OF OKLAHOMA)

We, the undersigned, are currently members of the Myelomeningocele Team or the Administration at Oklahoma Children's Memorial Hospital. The purpose of this team is to provide a multi-disciplinary approach in order to facilitate and provide the optimal level of care for newborns and permanent follow-up of myelomeningocele patients. As part of this approach the team assists the family with understanding and preparing for the consequences of this condition. The team is always available for any type of consultation.

By providing this approach, the Myelomeningocele Team is best able to be of service to the family. Unless a newborn child is so profoundly ill that to provide treatment would only prolong the act of dying, then the full spectrum of medical treatment is aggressively provided. This team does not now nor to any members' knowledge have they ever made any recommendation to a family on the basis of a quality of life formula, race, economic status, or any other non-medical considerations.

Michael Pollay
Michael Pollay, M.D.
Myelomeningocele Team Member

Signed and sworn before me this 20th day of May, 1985.

_______________, NOTARY PUBLIC
My commission expires April 5, 1986

David A Yngve
David A. Yngve, M.D.
Myelomeningocele Team Member

Signed and sworn before me this 20th day of May, 1985.

_______________, NOTARY PUBLIC
My commission expires April 5, 1986

William F. Barnes, M.D.
Myelomeningocele Team Member

Signed and sworn before me this 22nd day of May, 1985.

_______________, NOTARY PUBLIC
My commission expires April 5, 1986

Harriet Coussons, MD
Harriett Coussons, M.D.
Myelomeningocele Team Member

Signed and sworn before me this 21st day of May, 1985.

_______________, NOTARY PUBLIC
My commission expires April 5, 1986

Laura [illegible]ck, PA-C
Myelomeningocele Team Member

Signed and sworn before me this 20th day of May, 1985.

Shirley, NOTARY PUBLIC
My Commission expires April 5, 1986

Ruth
Ruth Tatyrek, MSW
Myelomeningocele Team Member

Signed and sworn before me this 21st day of May, 1985.

Shirley, NOTARY PUBLIC
My commission expires April 5, 1986

Owen M. Rennert, M.D.
Chief of Staff
Oklahoma Children's Memorial Hospital

Signed and sworn before me this 22nd day of May, 1985.

Shirley, NOTARY PUBLIC
My commission expires April 5, 1986

Donald F. Doznitz
Administrator
Oklahoma Children's Memorial Hospital

Signed and sworn before me this 20th day of May, 1985.

Shirley, NOTARY PUBLIC
My commission expires April 5, 1986

Antonio A. Padilla
Chief Executive Officer
Oklahoma Teaching Hospitals

Signed and sworn before me this 22nd day of May, 1985.

Shirley, NOTARY PUBLIC
My commission expires April 5, 1986

OKLAHOMA CHILDREN'S MEMORIAL HOSPITAL
INFANT CARE REVIEW COMMITTEE

I. MEMBERSHIP:

The membership of this committee will be appointed by the OCMH Chief of Staff and the OTH Executive Chief of Staff. The committee membership will include, at a minimum, the following:

(1) at least two physicians who practice pediatrics, pediatric surgery, or a surgical subspecialty practice serving primarily pediatric patients and who are members of an OTH medical staff;

(2) a member of the legal profession (other than the primary OTH legal counsel);

(3) a hospital administrator;

(4) a practicing pediatric registered nurse (R.N.);

(5) a doctoral level specialist in developmental disabilities;

(6) a representative of the lay public.

A physician member will be appointed as chairman by the chief of staff.

II. PURPOSES:

The purposes of the committee will be the following:

********** (A) to develop and implement standards, policies, and procedures for the Oklahoma Teaching Hospitals to assure that potentially medically beneficial treatments and/or nourishment be provided for all infants regardless of handicap or anticipated physical or mental impairments. These standards will be designed to respect reasonable medical judgements and will be directed by the principles stated in:

Amendment

Submitted to and
approved by the
Governing Body
12-04-84

(1) 45CFR 84.55 and Appendix C of 45CFR Part 84 (published in the Federal Register, January 12, 1984.

(2) House Bill No. 1133 (1984 Okla. Sess. Laws Serv., Ch. 120, p.390) (West)(to be codified as 10 O.S. §1101) and Section 18, House Bill No. 1528 (effective July 1, 1984).

(3) "The Principles of Treatment of Disabled Infants", published by the American Academy of Pediatrics on November 29, 1983, where not inconsistent with the federal and state provisions above. ***********

(B) to provide emergency review of selected cases in which withdrawal or withholding of life-sustaining therapy is contemplated, particularly those cases in which there is concern by the patient's caretakers or parents that the infant's rights to care are in jeopardy. Such emergency review may be sought on a 24 hour basis at the request of the ICRC or the hospital staff, or the infant's parent or guardian.

(C) to review regularly and retrospectively records involving withholding or withdrawal of therapy from infants to assure compliance with the established standards for care.

III. DETAILS OF COMMITTEE FUNCTION:

(A) Regular meetings will be held at a monthly interval.

(B) A quorum will be determined by attendance of 51% of the membership and must include at least 2 physician members in attendance.

(C) A majority shall consist of 51% of the membership present and voting.

(D) Each committee member will designate an alternate, who will be available on an ad hoc basis in the regular member's absence.

(E) Emergency meeting of the committee to review specific cases will be convened by the chairman as needed, within 24 hours notice to the membership.

(F) All deliberations of the committee shall be kept confidential, and shall be released to government authorities only as required by law or court order or after clearance by the hospital's legal counsel.

(G) All guidelines and policies of the ICRC will be reviewed by the hospital's legal counsel to assure conformity with the hospital's by-laws, rules, and regulations.

(H) All guidelines and policies must be approved by the respective hospital's Chief of Staff and Executive Committees, by the OTH

Executive Chief of Staff, by the Director of the Department of Human Services, and by the governing body of the Department of Human Services.

IV. GENERAL PRINCIPLES GOVERNING CARE OF THE SEVERELY HANDICAPPED INFANT:

(A) Beneficial medical therapy for a life-threatening condition shall be provided for all infants regardless of mental or physical handicap.

(B) The determination of "medically beneficial" therapy shall be made on the basis of a total evaluation of each patient's medical status.

(C) Appropriate care shall be provided to all infants regardless of financial or social resources.

(D) All infants will be provided with warmth, nourishment, and routine care.

(E) Medical care beyond basic nourishment and sustenance is not required for dying infants.

(F) Patients judged to be dead ("brain dead") by currently accepted medical criteria need receive no further medical care.

(G) In all instances, parents and legal guardians of all infants must be informed of their infant's condition and must be informed of and involved in all decisions concerning the appropriateness of the withholding or withdrawal of care from the infant.

(H) Specific standards for the care of specific conditions will be made consistent with the principles noted above in II.A., and after consultation with appropriate medical specialists within the hospital and after review of the collective medical knowledge and experience with these conditions.

Approved Infant Care Review Committee

March 15, 1984

Approved by Medical Care Committee	4/09/84
Approved by Executive Committee	4/30/84
Approved by Governing Body	7/12/84(OCMH Exec. Cmte. Minutes)
Approved by Governing Body	9/25/84
AMENDMENT approved by Governing Body	12/04/84

ATTEST:

(SEAL) Sharon Sharp

Sharon Sharp, Secretary to Commission

EXCERPT FROM MINUTES:

MEETING OF OKLAHOMA COMMISSION FOR HUMAN SERVICES

February 28, 1984

ATTEST:

(SEAL)

Sharon Sharp
Sharon Sharp, Secretary to Commission

REGULATIONS ON HEALTH CARE FOR HANDICAPPED INFANTS

Mr. Fulton discussed a memorandum mailed in advance to the Commission concerning Federal "Baby Doe" Regulations. This memo sets out the recommendations of a task force which was formed by the Department and headed by Dickye Mines to develop policies and procedures for consideration by the Commission. Item c of the memorandum still requires work and the detailed procedures will come back to the Commission for further review. The Director recommended the Commission to approve the three procedures set out in the memorandum as the components of the implementation process on the understanding that there is still work to be completed on item c. The policy must be in effect by April 13th.

Commissioner Gilbert made a motion to approve the procedures as recommended by the Director. Commissioner Ward seconded the motion.

Voting aye: Commissioners Farha, Furr, Gilbert, Hartley,
Walters, Ward, Way, Chairman Barnes.
Unanimously adopted.

Chairman Barnes then recessed the meeting for a short break.

STATE OF OKLAHOMA
DEPARTMENT OF HUMAN SERVICES

To: Commission for Human Services
Date: February 21, 1984

From: Robert Fulton
Director

Attention:

Subject: **Federal "Baby Doe" Regulations**
Non-Discrimination in Programs and Activities Receiving or Benefiting from Federal Financial Assistance--Handicapped Infants
Effective Date: February 13, 1984

In Reply—Address to
Attention: ________________________

The final Federal rules regarding medical treatment for handicapped infants (also known as the "Baby Doe" regulations) have recently been passed. The major elements of the final rules are:

1) The Federal government encourages hospitals to establish review procedures regarding life and death decisions affecting seriously ill newborns.

2) Informational notices regarding the legal rights of handicapped infants must be posted in hospitals.

3) State child protective services agencies must have established procedures for applying their own state laws protecting children from medical neglect.

4) Interpretive guidelines require that health care providers not withhold nourishment or medically beneficial treatment from the handicapped infant solely on the basis of present or anticipated physical or mental impairments. However, it does not interfere with reasonable medical judgements nor require provision of futile treatment.

5) Guidelines are also set for HHS investigations of alleged civil rights violations relating to health care for handicapped infants.

State child protective services agencies have 60 days and hospitals have 30 days within which to establish and maintain methods of administration and procedures.

A task force was formed to set Department's policies and procedures to be approved by the Commission. Following are the three major procedures which will need Commission approval:

a) Infant Care Review Committee:

This was not required but it was encouraged. OTH will follow the recommended guidelines. A review committee, headed by Doctor Mary Anne McCaffree, has been appointed. When a case is reviewed by this Committee, the Protective Services Unit of DHS will also be notified. If the Protective Services Unit is notified first, they will contact the hospital review committee.

b) Posting of Informational Notice:

The Federal Government has sent to each hospital receiving Federal funds a copy of the final regulations. It will be their responsibility to post the notices as outlined in the regulations. The Department is sending to each hospital the phone number of the DHS county office to which calls of alleged child abuse or neglect should be reported, the statewide child abuse hotline number, and the Federal hotline number which is already listed in the regulations. The DHS Audit and Review Division makes a yearly inspection for compliance with Federal civil rights of the handicapped requirements and will add checking of the Baby Doe postings to its inspections.

c) Responsibilities of DHS for Child Protective Services:

There is already in place in each county a procedure for receiving of reports of child abuse as required by State and Federal Law. This added responsibility will be handled in the same manner as all other child abuse incidents with the exception that as soon as a possible incident is reported the county staff will call the State Office Child Abuse Unit. It will be the State Office's responsibility to assure that the Federal Office of Civil Rights is notified of each incident. Written policies and procedures will be issued prior to the deadline date of April 13, 1984.

Fritz Aurin and Deborah Rothe have been in touch with Ms. Eleanor Hadad with the Office of Civil Rights in the HHS Regional Office in Dallas. There are questions regarding the definition of "infant" which she plans to clear through the HHS office in Washington. She has also assured the Department that they (HHS) have been responsible for notifying all hospitals. She further clarified that the rules applied only to hospitals and not individual doctors or local health clinics.

With the policies and procedures described above, it is our opinion DHS will be able to make an assurance to HHS that all aspects of the regulations will be implemented.

Thank you for consideration of this request.

Robert Fulton

EXCERPT FROM MINUTES:

MEETING OF OKLAHOMA COMMISSION FOR HUMAN SERVICES

March 27, 1984

ATTEST:

(SEAL)

Sharon Sharp

Sharon Sharp, Secretary to Commission

REGULATIONS ON HEALTH CARE FOR HANDICAPPED INFANTS

The Director discussed briefly the procedures approved at the last meeting regarding the Federal "Baby Doe" Regulations. He reviewed the original memo to the Commission which stated that written policies and procedures would be issued at a later date. had informed the Commission at the last meeting that such policies and procedures would be presented at this meeting. The Commission was furnished in advance with a copy of the proposed policies and procedures regarding alleged medical neglect of handicapped infants (attached).

Commissioner Way made a motion to approve the policies and procedures as presented by the Director. Commissioner Farha seconded motion.

Voting aye: Commissioners Farha, Furr, Gilbert, Greer,
Hartley, Ward, Way, Chairman Barnes.
Unanimously adopted.

Re: Federal "Baby Doe" Regulations-

These procedures will be issued by 04-06-84 in the protective Services Handbook and in corporated in Manual Section 620 when it is reissued.

CHILD WELFARE PROCEDURE - ALLEGED MEDICAL NEGLECT OF HANDICAPPED INFANTS

Every report alleging denial of medically beneficial treatment to a handicapped infant shall be promptly investigated and preventive services offered.

Referrals will generally be made to CWU via the county office (as in the case of most other abuse/neglect referrals) or via the statewide child abuse hot line. These phone numbers are required to be posted by the medical provider along with the HHS toll-free number (800-368-1019.)

When such referrals are received, the county office shall immediately notify State Office, Child Abuse Section. The state office is responsible for statewide tracking and notifying the Federal Office of Civil Rights.

Generally, the investigative and post-investigative procedure in these cases will be the same as in other investigations of reported abuse/neglect. The investigation shall be conducted as expeditiously as possible and the Report To The District Attorney, CSU-14-A, submitted promptly as usual.

In the event court intervention is felt to be warranted, appropriate steps should be taken as in other abuse/neglect cases. However, State Office, Child Abuse Section shall also be immediately advised. In the event it becomes necessary to apprise the Office of Civil Rights of the situation prior to completion of the investigation, this shall be the responsibility of the State Office.

Although it is recognized that protective services workers do not usually have the medical expertise necessary to make a determination regarding appropriate medical care, it is also recognized that the workers do have the necessary knowledge and skill to investigate and draw a conclusion based on interviews with and statements taken from qualified medical care providers.

In many hospitals, Infant Care Review Committee (ICRC) will be established for the purpose of reviewing the care provided to critically ill handicapped infants. The establishment of the ICRC is a recommendation rather than a requirement, however. Where there is an ICRC, the protective services worker shall consult with the ICRC as a part of the investigation. In situations where there is not an ICRC, other appropriate medical personnel shall be interviewed.

Generally, the investigation shall include interviewing the complaintant; the parents; obtaining the infant's diagnosis, prognosis, and recommended course of treatment from the attending physician; and interviewing either an ICRC representative and/or other medical personnel as appropriate to the individual case.

Appendix E

Federal Affected Agency Answers

DEPARTMENT OF HEALTH & HUMAN SERVICES
Office of Inspector General
Washington, D.C. 20201

OCT 12 1988

Mr. William J. Howard
General Counsel
United States Commission
on Civil Rights
1121 Vermont Avenue, N.W.
Washington, D.C. 20425

Dear Mr. Howard:

We have received your letter of September 20, 1988, with portions of the draft report on medical discrimination against handicapped infants prepared by the U.S. Commission on Civil Rights. Based on our review of the draft chapters, it appears that you have misinterpreted the purpose and intent of the Office of Inspector General (OIG) inspection on the baby doe program. Our comments are as follows:

Chapter 12. The Role and Performance of the Federal Government

o Your statement on page two that the OIG study was conducted "in response to the requirement of the Child Abuse Amendments..." is incorrect. The study was conducted in response to a request from the U.S. Surgeon General and the Office of Human Development Services, Administration for Children, Youth and Families.

o Also, your statement on page two that Inspector General personnel did not understand the requirements of the child abuse amendments and did not make appropriate inquiries to determine whether they are being carried out, indicates your lack of understanding of the purpose and intent of our study. Our next comment reinforces this point.

o On page three, you state that the OIG failed to review the facts in unreported cases considered by hospital infant care review committees. The purpose of our hospital visits was to determine how hospital committees are structured and functioning to deal with potential baby doe situations. It was never our intent to review individual case files. As you know, while the Department of Health and Human Services did publish model guidelines for infant care review committees, there is no Federal requirement regarding the establishment, structure or functioning of such committees in hospitals.

- Your statement on page four about our description of the infant bioethical review committees at four affiliated hospitals in New York is misleading. The purpose of this portion of the report was simply to serve as a reference to other hospitals considering the establishment of similar committees.

Chapter 10. Child Protective Service Agencies

- Your statements on pages 12 and 16 regarding the "official" nature of comments from respondents from State Child Protective Service (CPS) agencies are incorrect. The comments made by respondents in this study were the personal opinions of professional staff familiar with the baby doe program and how it fits into the State's entire range of child protective services. They did not represent the "official and public position" of State CPS agencies.

We appreciate the opportunity to comment. If your staff have questions, they may contact Ta Zitans at 245-2456.

Sincerely yours,

Richard P. Kusserow
Inspector General

U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

OCT 26 1988

William J. Howard, Esquire
General Counsel
United States Commission On
Civil Rights
1121 Vermont Avenue, N.W.
Washington, D.C. 20425

Dear Mr. Howard:

I have reviewed the September 19, 1988, draft report of the United States Commission on Civil Rights on medical discrimination against handicapped infants. The description of the activities of the Civil Rights Division with respect to the matters discussed in the report appears accurate. I would note, however, that in 1983 the Department of Health and Human Services referred a matter to the Division involving possible discrimination against a newly born handicapped infant at a hospital in Stoneybrook, New York. We sought to obtain certain medical records, but were blocked in our efforts by a federal district court in New York. If you believe information relating to the Stoneybrook situation would be useful to include in your report, I will have the appropriate records retrieved and provide you with whatever details you need.

If I can be of any further assistance, please feel free to contact me.

Sincerely,

Wm. Bradford Reynolds
Assistant Attorney General
Civil Rights Division

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of
Human Development Services

Assistant Secretary
Washington DC 20201

T 31 1988

William J. Howard
General Counsel
United States Commission
on Civil Rights
1121 Vermont Avenue, N. W.
Washington, D.C. 20425

Dear Mr. Howard:

I am writing in response to your request for comment on Chapter Ten of the Draft Report of the U.S. Civil Rights Commission, entitled "Child Protective Services Agencies and Their Enforcement of the Child Abuse Amendments of 1984." This chapter concerns State implementation of the provisions of the 1984 amendments to Public Law 100-294 concerning medical neglect of handicapped infants.

We are extremely concerned about your findings which indicate that a number of State Child Protective Service (CPS) agencies may fail to meet the requirements for Federal funding as provided for in 45 CFR 1340.15, and your statement that the Department of Health and Human Services has incorrectly certified them as eligible. The issues you raise are indeed serious.

Your report also makes clear that in addition to the possible deficiencies of specific State programs, there are larger societal attitudes and practices which may complicate the fulfillment of Congressional intent in this matter. These include the ambivalence of some CPS agency staff about whether the withholding of medically indicated treatment from disabled infants with life-threatening conditions is appropriately a CPS responsibility; the possible ambivalence on the part of some social work and medical professionals about whether this rightfully should be a decision made by a child's parents with advice from a physician; and as also noted in the report, societal attitudes which often view disabled children as a burden to their parents and communities.

In 1985, when the first grants were awarded to protect infants from medical neglect, the Department followed the procedures set forth in Section 45 1340.15 of the Code of Federal Regulations for certifying the eligibility of States to receive funds. This involved the review of State statutes, programs, policies and procedures for compliance with the requirements of the legislation. Each year following 1985, States have been asked to submit any changes in any of these documents and to certify that they remain eligible. Each year the Regional Administrators of the Office of Human Development Services, working with other regional office staff and the regional counsel, have had the responsibility for reviewing the materials submitted by the States and forwarding to the Commissioner of the Administration for Children, Youth and Families their opinion as to whether the States are in compliance. Funds are awarded by the regional offices to those States that are in compliance based on that verification. In any instance of denial, the Assistant Secretary makes the final determination of ineligibility. So far as we know, only States in compliance have been funded.

Because of the information compiled in your report, we will take two actions. First, we will convene a staff workgroup in the Office of Human Development Services, which includes the Administration for Children, Youth and Families and the Administration on Developmental Disabilities. These agencies have a particular interest, responsibility and expertise in this subject. This group will review our current policies and instructions to determine if there are ways in which we can improve the administration of the Federal program and the use of Federal funds to accomplish its purposes. As part of this effort we will consult with selected States, individuals and organizations outside the government who have a particular interest or expertise. We especially would seek advice on how we can help States encourage and strengthen information, education and training programs so that all appropriate cases of medical neglect are identified and services provided.

These efforts may assist us in obtaining more accurate data about the actual number of cases of medical neglect of handicapped infants, and developing strategies for more effectively serving this population.

Second, we will review the eligibility of each State cited in your report, paying special attention to those areas of concern that you have identified.

Our efforts will be facilitated if we can review the complete draft of your report and all supporting documentation of your findings, including reference materials such as citations from State laws, regulations, manuals and protocols. We will appreciate your sharing this additional information with us.

Please be assured of our commitment to ensure that all States which receive child abuse State grants meet all of the requirements of Federal law and regulations.

Sincerely,

Sydney Olson

Sydney Olson
Assistant Secretary for
Human Development Services

Appendix F

In re Infant Doe

Declaratory Judgment in the Infant Doe Case

In the Circuit Court of the County of Monroe
State of Indiana

In the Matter of the Treatment
and Care of Infant Doe — Cause No. GU 8204-004A

Declaratory Judgment

This matter came to be heard by the Court under certain extraordinary conditions concerning the emergency care and treatment of a minor child born at the Bloomington Hospital.

The Court was contacted at his residence by representatives of the Bloomington Hospital. On the basis of representations made by those representatives, the Court quickly determined that an extreme emergency existed.

The Court further determined that the Judge of the Monroe Circuit Court had been contacted concerning this matter and was unable to attend the emergency hearing, and the Court personally contacted the judge of the Monroe Circuit Court who directed this Court to proceed with hearing. Thereafter, hearing was held on the Sixth Floor of the Bloomington Hospital at approximately 10:30 P.M., Saturday, the 10th day of April, 1982.

The following persons were present: John Doe, natural father of Infant Doe, with counsel, Andrew C. Mallor, Esquire; Maggie Keller, Gene Perry, Administrative Vice-Presidents of Bloomington Hospital; Dr. Walter L. Owens, Dr. William R. Anderson, Dr. Brandt L. Ludlow, obstetricians admitted to practice in the State of Indiana with privileges at Bloomington Hospital, Doctor Owens being the obstetrician in attendance at delivery at Infant Doe; Dr. Paul J. Wenzler, family practitioner with pediatric privilege at Bloomington Hospital and who has attended to Mr. and Mrs. Doe's other two children after their birth; Dr. James J. Schaffer and Dr. James J. Laughlin, pediatricians holding pediatric privileges at Bloomington Hospital. (Mrs. Doe was physically unable to attend.)

The Court thereafter heard evidence. Doctor Owens spoke for and on behalf of the obstetric group that delivered the Infant Doe, advising the Court that at approximately 8:19 P.M. on the evening of April 9, Infant Doe was born to Mary Doe in an uneventful delivery, but that shortly thereafter it was very apparent that the child suffered from Down's syndrome, with the further complication of trachioesophageal fistula, meaning the passage from the mouth to the stomach had not appropriately developed and, in fact, were the child to be fed orally, substances would be taken into the lungs and the child most likely would suffocate.

Doctor Owens further stated that he had been previously advised that Doctor Wenzler would serve as practitioner for Infant Doe and that he was further advised that Doctor Wenzler, when faced with extraordinary cases, routinely consulted with Doctor Schaffer. Doctor Schaffer was at the Bloomington Hospital at that time and was called by Doctor Owens and was requested to examine the baby. Doctor Wenzler was notified. Doctors Owens, Schaffer and Wenzler consulted; Doctors Wenzler and Schaffer indicated that the proper treatment for Infant Doe was his immediate transfer to Riley Hospital for corrective surgery. Doctor Owens, representing the concurring opinions of himself, Doctors Anderson and Ludlow, recommended that the child remain at Bloomington Hospital with full knowledge that surgery to correct trachioesophageal fistula was not possible at Bloomington Hospital and that within a short period of time the child would succumb due to inability to receive nutriment and/or pneumonia.

His recommended course of treatment consisted of basic techniques administered to aid in keeping the child comfortable and free of pain. Doctor Owens testified that, even if surgery were successful, the possibility of a minimally adequate quality of life was non-existent due to the child's severe and irreversible mental retardation.

Doctor Schaffer testified that Doctor Owens' prognosis regarding the child's mental retardation was correct, but that he believed the only acceptable course of medical treatment was transfer to Riley Hospital in Indianapolis for repair of trachioesophageal fistula.

Doctor Wenzler concurred in Doctor Schaffer's proposed treatment. Doctor Laughlin testified that he concurred in the opinions of Doctors Schaffer and Wenzler, and he differed with Doctor Owens' opinion in that he knew of at least three instances in his practice where a child suffering from Down's syndrome had a reasonable quality of life. However, he related no knowledge of treatment of children with co-existent maladies of Down's syndrome and trachioesophageal fistula.

Doctor Owens testified that he presented Mr. and Mrs. Doe with the two recommended courses of treatment and requested that they come to a decision. Doctor Owens understood that Doctors Schaffer and Wenzler also discussed their recommendations with Mr. and Mrs. Doe.

Mr. Doe testified that he had been a licensed public school teacher for over seven years and had on occasion worked closely with handicapped children and children with Down's syndrome and that he and his wife felt that a minimally acceptable quality of life was never present for a child suffering from such a condition. Mr. Doe was lucid and able to make an intelligent, informed decision.

Mr. Doe testified that, after consulting with Doctors Owens, Schaffer, Wenzler and Laughlin, he and his wife have determined that it is in the best interest of the Infant Doe and the two children who are at home and their family entity as a whole, that the course of treatment prescribed by Doctor Owens should be followed, and at approximately 2:45 P.M., he and his wife, in the presence of each other and witnesses, signed a statement directing Doctor Owens to proceed with treatment of the infant, the content of said statement, omitting names and dates, is as follows:

> The undersigned being the parents of Infant ________, born _________, at Bloomington Hospital, have had explained to them and they acknowledge that they understand, the course of this treatment for Infant ________ as indicated appropriate for Infant ________ by Doctors Walter L. Owens, James J. Laughlin, James J. Schaffer and Paul J. Wenzler.
>
> Acknowledging their understanding and the consequences of all of the above proposals made by all of the above four physicians, that they direct that the course of treatment shall proceed as directed by Dr. Walter Owens, M.D., who does not have privilege to practice pediatrics at Bloomington Hospital.

Mr. Len E. Bunger, on behalf of Bloomington Hospital, made a statement that it was the hospital's primary function to reduce morbidity and mortality and that the hospital did not have the knowledge or the authority to make diagnoses or to prescribe treatment and, for that reason, had requested the Court to make a ruling in this matter.

The Court, having heard evidence, recesses and thereafter determines as follows:

1. All qualified persons available to present evidence in this matter were present and thus appointment of a guardian ad litem for Infant Doe was not required to proceed further in this hearing.

2. The Court appeared solely as a representative of the State of Indiana and the laws of the State of Indiana require that the parents be sufficiently informed, as they are in this instance, and any personal feelings of the Court should not intervene.

Issue

Do Mr. and Mrs. Doe, as the natural parents of Infant Doe have the right, after being fully informed of the consequences, to determine the appropriate course of treatment for their minor child?

Conclusion

It is the opinion of this Court that Mr. and Mrs. Doe, after having been fully informed of the opinions of two sets of physicians, have the right to choose a medically recommended course of treatment for their child in the present circumstances.

Order

The Court, being sufficiently advised, now directs the Bloomington Hospital to allow treatment prescribed by Dr. Walter Owens, as directed by the natural parents, Mr. and Mrs. Doe, for the Infant Doe.

The Court further directs that the Clerk of this Court assign a cause number and enter this cause upon the guardianship docket and fee book of this Court.

The Court further appoints the Monroe County Department of Public Welfare as guardian ad litem for the Infant Doe to determine whether the judgment of this Court should be appealed.

Dated this 12th day of April, 1982.

JOHN G. BAKER
Judge, Monroe Superior Court
Division III, and as
Special Judge, Monroe Circuit Court

Appendix G

Section 504 Final Rule

federal register

Thursday
January 12, 1984

Part III

Department of Health and Human Services

Office of the Secretary

45 CFR Part 84

Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants; Final Rule

TABLE OF CONTENTS

SUPPLEMENTARY INFORMATION

I. Synopsis..1622

II. Background...1622

III. Provisions of the Final Rules.............................1623

A. Infant Care Review Committees...............................1623

B. Informational Notice..1625

C. Responsibilities of Child Protective Service Agencies.......1626

D. Expedited Access to Records.................................1627

E. Expedited Action to Effect Compliance.......................1628

F. Guidelines Relating to Health Care for Handicapped Infants..1628

G. Interpretative Guidelines Relating to the Applicability of Section 504..1629

Medically Beneficial Treatment.................................1629

Parental Decisions...1631

H. Guidelines for HHS Investigations Relating to Health Care for Handicapped Infants...............................1632

Conduct of Investigations......................................1632

Use of Medical Consultants.....................................1633

Prompt Report of Investigative Findings........................1634

Confidentiality of Records.....................................1634

IV. Related HHS Activities.....................................1635

V. Additional Analysis of Comments.............................1635

A. Legal Issues..1635

Statutory Construction of Section 504..........................1635

Separating the "Handicap" from the Condition Requiring Treatment....................1636

Applicability of Section 504 When Hospital is Incapable of Providing Treatment....................1637

Responsibilities of Hospitals as Opposed to Physicians............1637

Applicability of Section 504 to Adults............................1637

Limitations on Obligations Imposed by Section 504.................1638

Medicare and Medicaid as "Federal Financial Assistance"...........1638

"Program or Activity" Receiving Federal Financial Assistance......1640

Services vs. Employment as Jurisdictional Limitation..............1641

B. Enforcement Processes..1641

Sanction for Noncompliance..1641

OCR Investigations at Strong Memorial Hospital and Vanderbuilt University Hospital..1642

Danger of Overtreatment...1643

C. Alternative Approaches...1644

AMA Proposal: Further Study Prior to Action.......................1644

D. Factual Basis for Final Rules..................................1645

NPRM Explanation..1645

Evidence of Problems Submitted by Commentators.....................1645

OCR Investigations to Date..1646

E. Other Issues...1649

Self-Evaluation...1649

Information to Parents..1649

VI. Regulatory Information..1650

Severability..1650

Regulatory Impact Analysis..1650

Regulatory Flexibility Analysis...................................1650

Paperwork Reduction Act...1650

Department of Justice Review......................................1650

REGULATIONS

§84.55 Procedures relating to health care for handicapped infants......1651

- (a) Infant Care Review Committees..................................1651
- (b) Posting of informational notice..................................1651
- (c) Responsibilities of recipient state child protective services agencies..1651
- (d) Expedited access to records......................................1652
- (e) Expedited action to effect compliance..........................1652
- (f) Model Infant Care Review Committee..............................1652
  - (1) Establishment and purpose..1652
  - (2) Organization and staffing..1652
  - (3) Operation of ICRC..1652
    - (i) Prospective policy development...............................1652
    - (ii) Review of specific cases.......................................1653
    - (iii) Retrospective record review...................................1653
  - (4) Records...1653

Appendix C—Guidelines Relating to Health Care for Handicapped Infants..1653

- (a) Interpretative guidelines relating to the applicability of this part to health care for handicapped infants.............1653
- (b) Guidelines for HHS investigations relating to health care for handicapped infants...1653

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary

45 CFR Part 84

Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants

AGENCY: Office of the Secretary, HHS.

ACTION: Final rules.

SUMMARY: These are final rules on procedures and guidelines relating to nondiscrimination on the basis of handicap in connection with health care for handicapped infants. These rules are issued under the authority of section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap in programs and activities receiving Federal financial assistance.

EFFECTIVE DATE: February 13, 1984.

FOR FURTHER INFORMATION CONTACT: Susan Shaloub, Office for Civil Rights, Department of Health and Human Services, 330 Independence Avenue, SW., Room 5514, Washington, D.C. 20201; telephone (202) 245-6585. TDD No. (202) 472-2916.

SUPPLEMENTARY INFORMATION:

I. Synopsis

These rules are the product of a careful analysis of nearly 17,000 comments submitted to the Department during the comment period provided by the proposed rules of July 5, 1983. On the basis of this analysis, the Department has made significant modifications to the proposed rules. These modifications are designed to establish a framework under which the substantial controversy that has attended the Department's efforts to strengthen enforcement of section 504 in this area can be replaced by a more cooperative effort involving the Federal Government, the medical community, private advocacy groups and state governments.

These final rules continue the Department's efforts to put in place an effective mechanism for enforcing section 504 in connection with health care for handicapped infants.

But they also initiate new efforts to make unnecessary the use of those Federal enforcement mechanisms by encouraging hospitals to establish policies and procedures to implement the principle that treatment decisions for handicapped infants be based on reasonable medical judgments, and medically beneficial treatment not be withheld solely on the basis of an infant's present or anticipated mental or physical impairments.

In seeking to forge a cooperative approach, the Department is encouraged by the recent development of "Principles of Treatment of Disabled Infants" by the following major medical and disability organizations: American academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Association for Retarded Citizens, Down's Syndrome Congress, Spina Bifida Association of America, American Coalition of Citizens with Disabilities, The Association for the Severely Handicapped, American Association on Mental Deficiency, and American Association of University Affiliated Programs for the Developmentally Disabled. Announced November 29, 1983, in Washington, D.C., these principles state:

> When medical care is clearly beneficial, it should always be provided. * * * Considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.
>
> It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.
>
> In case where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. * * * When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

In the issuance of these final rules, the Department seeks to build upon the spirit of cooperation underlying this landmark statement of principles. The major elements of the final rules are as follows:

First, the Department adopts the recommendation of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research that the Federal government encourage hospitals to establish review procedures concerning life and death decisions affecting seriously ill newborns. The rules include a model Infant Care Review Committee to assist hospitals in this effort.

Second, the rules require the posting in hospitals of an informational notice regarding the legal rights of handicapped infants. The notice requirements have been revised to permit hospitals to highlight their own policies and internal review procedures, in addition to the federal law and government contact points.

Third, the rules require that state child protective services agencies have established procedures for applying their own state laws protecting children from medical neglect.

Fourth, the appendix to the rules sets forth interpretative guidelines for applying the law in these cases. These guidelines restate the Department's interpretation that section 504 requires that health care providers not withhold nourishment or medically beneficial treatment from a handicapped infant solely on the basis of present or anticipated physical or mental impairments, but it does not interfere with reasonable medical judgments, nor require the provision of futile treatments.

Fifth, the appendix to the rules sets forth guidelines for HHS investigations of alleged civil rights violations relating to health care for handicapped infants. These guidelines provide for the participation of hospital Infant Care Review Committees, the avoidance of unnecessary investigations, the involvement of qualified medical consultants, and the protection of confidential information.

The Department hopes the issuance of these rules, which become effective in 30 days, will end the controversy that has surrounded their development. But more importantly, it is hoped the rules will foster a new process of cooperative efforts and sensible approaches to advance the principle that life and death medical treatment decisions be based on informed judgments of medical benefits and risks, and not on stereotypes and prejudices against handicapped persons.

II. Background

On April 30, 1982, President Reagan instructed the Secretary of Health and Human Services:

> to notify health care providers of the applicability of section 504 of the Rehabilitation Act of 1973 to the treatment of handicapped patients. That law forbids recipients of federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps. Regulations under this law specifically prohibit hospitals and other providers of health services receiving federal assistance from discriminating against the handicapped.
>
> * * * * *
>
> Our nation's commitment to equal protection of the law will have little meaning

> if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support federal laws prohibiting discrimination against the handicapped, and remain determined that such laws will be vigorously enforced.

The President's instructions followed reports of the death, in Bloomington, Indiana, of an infant with Down's syndrome, from whom available surgical treatment to repair a detached esophagus was withheld.

On May 18, 1982, HHS issued to approximately 7,000 hospitals a notice stating:

> Under section 504 it is unlawful for a recipient of federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) the withholding is based on the fact that the infant is handicapped; (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

Soon after this notice, the HHS Office for Civil Rights (OCR) established expedited investigative procedures to deal with any case of a suspected discriminatory withholding of lifesustaining nourishment or medical treatment from a handicapped infant.

On March 7, 1983, HHS issued, with a scheduled effective date of March 22, 1983, an interim final rule requiring recipient hospitals to post "in a conspicuous place" in pertinent wards a notice advising of the applicability of section 504 and the availability of a telephone "hotline" to report suspected violations of the law.

On April 14, 1983, the Honorable Gerhard Gesell, United States District Judge for the District of Columbia, declared the interim final rule invalid on the grounds that it was "arbitrary and capricious" and that there was inadequate justification for waiving a public comment period prior to issuance of the regulation. *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395 (D.D.C. 1983). Judge Gesell declined to order the Department to discontinue use of the hotline.

On July 5, 1983, HHS issued a proposed rule in which the notice requirement was revised; provisions were added concerning state child protective service agencies; an appendix of standards and examples was added; and a 60-day comment period was provided. 48 FR 30846.

The Department received 16,739 comments, of which 16,331 (97.5%) supported the proposed rule, and 408 (2.5%) opposed it. Other aggregate descriptions are:

—Of 322 nurses, 314 (97.5%) supported, and 8 (2.5%) opposed it.
—Of 141 pediatricians or newborn care specialists, 39 (27.7%) favored, and 102 (72.3%) opposed it.
—Of 253 physicians, not including pediatricians or newborn care specialists, 140 (55.3%) favored, and 113 (44.7%) opposed it.
—Of 137 comments from hospital officials and medical, hospital, nursing and other health related association, 31 (22.6%) supported and 106 (77.4%) opposed it.
—Of 77 comments from associations representing the handicapped, all supported the proposed rule.
—Of 100 parents of handicapped persons, 95 (95%) supported and 5 (5%) opposed it.

In addition to the written comments received, a number of meetings were held after issuance of the proposed rule with representatives of interested groups. The principal HHS officials involved in these meetings were the Under Secretary and the Surgeon General. Minutes of these meetings were kept and have been included in the public comment file.

Every comment was read and analyzed. Readers determined whether the commenter was in favor of, or opposed to, the proposed rule and identified particular points made by the commenter. The decisions made by the Department in connection with the rule are based not on the volume of comments advancing any point, but on thorough consideration of the merits of the comments submitted.

III. Provisions of the Final Rules

A. INFANT CARE REVIEW COMMITTEES

The March 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research included the following recommendation:

> The Commission concludes that hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants. . . . Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be forgone. . . .
>
> Such a review could serve several functions and the review mechanism may vary accordingly. First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate.

In response to a question included in the preamble, the Department received many comments regarding hospital review boards. Many commenters who expressed opposition to the rule, particularly health care providers, expressed a strong preference for the hospital review board approach over the proposed rule or any implementation or enforcement of section 504. Others opposed hospital review boards, particularly as an alternative to the proposed rule and existing HHS procedures.

The American Academy of Pediatrics, which submitted the most detailed proposal, suggested, as an alternative to the proposed rule, that all hospitals, as a condition of participation in the Medicare program (not as a requirement of section 504), establish a review committee. Under this proposal (also endorsed by the National Association of Children's Hospitals and Related Institutions, and in concept, the American Hospital Association) the committee would have three functions: (1) To develop hospital policies and guidelines for management of specific types of diagnoses; (2) to monitor adherence through retrospective record review; and (3) to review, on an emergency basis, specific cases when the withholding of life-sustaining treatment is being considered. When the committee disagreed with a parental or physician decision to withhold treatment, the case would be referred to the appropriate court or child protective agency, and treatment would be continued pending a decision. Committee membership would include a hospital administrator, a representative of a disability group, a lay community member, a member of the hospital's medical staff, and a practicing nurse.

Among the arguments advanced in favor of the creation of hospital review boards, as a substitute for the approach set forth in the proposed rule, were:

(a) They would represent a cooperative approach between the government and the health care community, rather than a confrontational approach.

(b) They would provide a vehicle by which facility "self-evaluations" can be conducted.

(c) They would assure an indepth review by persons of varied perspectives of individual, complex cases involving critically ill infants.

(d) They would provide a mechanism for ensuring that hospitals, physicians and parents are informed of the most recent medical information concerning treatment of handicapped infants and of community services. counselling. parent support groups. and such alternative care options as adoption. foster care. and other out-of-home placements

(e) They would lead to the involvement of child protective agencies and of the courts where it is indicated that the interests of the child are not being served.

Many commenters who expressed support for the proposed rule also expressed strong opposition to the alternative approach of hospital review boards because:

(a) Such boards cannot replace State and federal government responsibilities to protect the rights of citizens. The use of review boards would not assure that all individuals with disabilities would receive nondiscriminatory treatment as guaranteed by section 504.

(b) Such boards are virtually untested as a viable mechanism to protect handicapped infants from discriminatory practices.

A number of commenters. including the American Medical Association. the Catholic Health Association. the Federation of American Hospitals. the American College of Hospital Administrators. the American College of Physicians. the American Nurses Association. and other medical groups. expressed support for the concept of review boards. but opposed any mandate that review boards be established. The AMA added:

> While we do not support federal intervention in treatment decisions concerning seriously ill newborns. the attention brought about by the government's action should provide a continued stimulus to develop mechanisms to deal with these sensitive matters without the intrusion of the federal government into an area where it does not belong.

Response

The Department believes there is much merit in many of the comments submitted both in favor of. and in opposition to. utilization of hospital review boards to assist in the development of standard policies and protocols and to review individual cases. The Department's conclusions are as follows.

First. the Department believes review committees cannot be given an exclusive role in reviewing medical decisions concerning the withholding or withdrawal of medical or surgical treatments from handicapped infants. and thus. cannot accept the proposal of hospital review boards as a *substitute* for mechanisms to enforce section 504.

The Department does not seek to take over medical decisionmaking regarding health care for handicapped infants. HHS agrees that the best decisionmakers are generally the parents and the physicians directly involved. However. there is. and must be. a framework within which the decisionmakers. the parents and physicians. operate.

That framework is established by laws. With respect to health care professionals providing services under programs or activities receiving federal financial assistance. the framework includes section 504. which prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. With respect to parents. the laws are state laws establishing limitations on parental authority. With respect to both the federal law and the respective state laws. each specifically provides implementation mechanisms involving government agencies.

The fundamental issue involved in deciding whether review boards should be a substitute for enforcement of section 504 is whether the legal framework within which the decisionmaking parents and physicians are supposed to function (and generally do function) will be utilized.

Under the proposal that review boards act in lieu of government. whether physicians or hospital review boards adhere to the principles of section 504 would be determined by those physicians and boards alone. Whether parents. physicians. or review boards adhere to state laws on the limitations of parental authority would be decided by the same physicians and boards. Whether they ever utilize the implementation schemes established by law to ensure that those principles are adhered to would also be decided by those parents. physicians. and review boards.

The Department concludes that the essential element of this alternative proposal—that it separates the process from the established legal framework governing decisionmaking by parents and physicians. with no meaningful provision to ensure that they function in accord with this framework—makes the proposal unacceptable as a substitute for the proposed rule. This alternative proposal simply does not provide sufficient safeguards that the requirements of section 504 will be met. Because section 504 is applicable to the provision of health care services to handicapped infants in programs and activities receiving Federal financial assistance. the Department believes it would not be justifiable for the Department to refrain from exercising a regulatory role to enforce the statute.

Second. the Department concludes that. although unacceptable as a substitute. review boards can be very valuable. *The Department agrees with* the rationale of the President's Commission and many commenters that input from a committee that includes individuals with medical expertise and people with non-medical perspectives and that is guided by proper standards and protocols can be very helpful in bringing about informed. enlightened and fair decisionmaking regarding these difficult issues. The Department. therefore. adopts the recommendation of the President's Commission that the government encourage establishment of hospital review boards.

Third. the Department concludes that the creation of hospital review boards should not be mandated by the Federal government. The Department agrees with the President's Commission that because review boards are "largely untried". they are not so demonstrably effective as to justify making them mandatory for nearly 7.000 hospitals nationwide. Also. there would be very substantial practical problems in seeking to enforce such a mandate with respect to so many hospitals. To make such a mandate viable. it would have to be accompanied by detailed standards on how to organize and operate the committee. The Department agrees with the President's Commission that flexibility is needed for each hospital to consider the best approach for itself. For example. the review board procedures may be unnecessary for small or rural hospitals that rarely encounter cases involving severely impaired newborns and that handle such cases by immediately transferring the infant to the appropriate specialty hospital.

In addition. in view of the strong opposition by major medical organizations to mandatory committees there would likely be protracted legal proceedings challenging the regulation. whether adopted pursuant to section 504 or pursuant to authority under the Social Security Act to establish conditions of participation and standards for the Medicare and Medicaid programs.

For these reasons. the Department has concluded that Infant Care Review Committees should be encouraged. but not mandated by the federal government.

Fourth. the Department concludes that the establishment of review boards will be facilitated by the development of a model committee. Therefore. § 84.55(f) of the rules sets forth a model Infant Care Review Committee (ICRC). This model calls for broad representation and significant involvement of the ICRC in developing standard policies and protocols for the hospital and in promptly reviewing specific cases. The model is based sustantially on comments submitted by the American Academy of Pediatrics.

The Department has revised the Academy's model somewhat to underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504, the recommendations of the President's Commission and the landmark "Principles of Treatment of Disabled Infants." The Department has also revised the Academy's model to provide, in connection with review of specific cases, for the designation of one member of the ICRC as "special advocate" for the infant. While recognizing that all members of the ICRC should be advocates for the best interests of the infant, the role of the special advocate will be to ensure that all considerations in favor of the provisions of life-sustaining treatment are fully evaluated and considered. As the President's Commission stated, "it is all too easy to undervalue the lives of handicapped infants." The special advocate feature of the model ICRC provides a mechanism to counteract this tendency.

This model is also consistent with the recommendations of the President's Commission and the comments of the American Hospital Association and other medical organizations. The Department also acknowledges the comment of the American Medical Association that the government's actions provide "a continued stimulus" for the medical community "to develop mechanisms to deal with these sensitive matters." HHS strongly encourages medical organizations to follow through on their suggestions and provide all possible assistance to their member institutions and medical professionals in establishing and operating these ICRC's.

B. INFORMATIONAL NOTICE

The proposed rules required that recipient hospitals post "in a conspicuous place in each nurse's station" of appropriate wards a notice stating:

> DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW.
>
> * * * * *
>
> Any person having knowledge that a handicapped infant is being discriminatory denied food or customary medical care should immediately contact:
>
> Handicapped Infant Hotline
>
> * * * * *
>
> Failure to feed and care for infants may also violate the criminal and civil laws of your state.

A number of commenters expressed a concern that the posting of the required notice would itself have a disruptive effect on the provision of health care to newborn infants by creating the impression to an infant's parents, already in a very stressful situation, that the physician, nursing staff, and hospital should not be trusted to provide proper care to their child. In connection with this point, the Catholic Health Association suggested that hospitals be permitted to use an alternative notice allowing the hospital to state its agreement with the policy of nondiscrimination and indicate the appropriate hospital contact person. Another comment suggested alternatives to posting, such as placing the notice on the admitting document or on consent forms used by the hospital.

Some commenters considered the wording of the notice very ambiguous in its references to "discriminatory failure" and "customary medical care" and in its failure to make reference to futile treatments, deference to legitimate medical judgments, the nonapplicability of section 504 to parental decisions, and many distinctions and nuances relating to the applicability of section 504 in this context.

Other criticisms were that the words "should immediately contact" improperly implied a legal obligation to report; the reference to "this facility" implied prior misconduct by that facility; and the reference to violations of "the criminal and civil laws of your state" is inappropriate because it does not relate to the purpose of the notice to inform people about civil rights protections.

A number of commenters suggested additions to the notice, including: a reference to the sanctions for noncompliance; express inclusion of handicapped infants born alive after abortions; reference to physical, mental, or emotional abuse or injury or withholding of fluids, oxygen, medications, warmth, and routine nursing care; and a statement that callers are not required to identify themselves.

Other commenters urged that hospitals be required to notify HHS that the notice has been posted.

Response

In an effort to accommodate many of these concerns, the Department has made a number of changes regarding the wording of the informational notice and the locations where it is to be posted. However, the Department remains convinced of the need for a notice to advise individuals in a position to know about potentially discriminatory conduct of the requirements of the law and of the mechanisms available to report suspected violations expeditiously so that, should a violation be occurring, corrective action can be taken in time to save the infant's life.

In many other contexts of civil rights enforcement and enforcement of scores of other statutes, speed is not essential because the victim of discrimination can be essentially "made whole" through reinstatement in a job, admission to a school or hospital, retroactive benefit payments, or the like. However, in the context of life and death medical decisions, the matter must be handled with the utmost urgency. For this reason, the Department continues to believe that it is essential to meaningful implementation of the requirements of section 504 to have a mechanism for immediate reports of suspected violations.

However, the Department has concluded that it can, without detracting from this overriding objective, eliminate the unintended adverse effects of the notice many commenters perceived. Therefore, the informational notice requirements set forth in § 84.55(b) reflect significant modifications from those set forth in the proposed rules.

First, the Department has adopted the suggestion of the Catholic Health Association that hospitals be permitted to post a notice reflecting that the hospital's policy is consistent with the nondiscrimination requirements of section 504 and that the hospital also has a mechanism to review suspected noncompliance with this policy. This change eliminates any perception that the notice implies improper conduct by the hospital.

The only requirement contained in the rule for the use of this notice (identified in the regulation as "Notice A") is that the content of the notice be truthful as it relates to that hospital. To be truthful, the hospital must have a policy that nourishment and medically beneficial treatment, as determined with respect for reasonable medical judgments, should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments. Furthermore, the hospital must have a procedure for review of treatment deliberations and decisions concerning health care for handicapped infants. Also, so that potential callers will be assured that the hospital's procedures will be implemented in good faith, the hospital's policies must provide for the confidentiality of the identity of, and prohibitions of retaliation against, potential callers who, in good faith and nonmaliciously, provide information about possible noncompliance. A hospital need not, in order to post Notice A, have an Infant Care Review Committee in conformance with the model ICRC, nor forego management prerogatives with respect to anyone who might abuse the hospital's procedures by, for example, willfully making false or malicious calls. Hospitals for which the content of "Notice A" is not truthful must post the notice identified as "Notice B."

Second, the requirement regarding the location where copies of the notice must be posted has been changed. Consistent with the Department's intent to target the notice to nurses and other health care professionals, the proposed rule required that the notice be posted at the nurses' stations of appropriate wards, rather than more generally in the wards as had been stated in the March interim final rule. In view of the concern expressed by a number of commenters that posting in the nurses' stations would continue to make the notice conspicuous to distressed parents, the final rules do not require that copies of the notice be posted at nurses' stations. Rather, the notice is to be posted at any location(s) where nurses and other medical professionals who are engaged in providing health care related services to infants will be aware of the content of the notice. Locations such as locker rooms and lounge areas will suffice as long as placement in these locations ensures that the appropriate personnel will see the notice. Under these circumstances the notice would not have to be posted at nurse's stations or any other location where posting would have adverse effects on parents. The number of copies which must be posted in the hospital is similarly determined on the basis of ensuring that the appropriate personnel will see it.

Third, in view of this more specific targeting, the size of the notice has been reduced from the 8½ x 11 inches requirement in the proposed rule (and the 17 x 14 inch notices distributed in connection with the March rule) to 5 x 7 inches.

Fourth, the wording of the informational notice has been revised in connection with the language which attempts to convey in simple terms the basic protection of the law. The new language reflects the law's deference to reasonable medical judgments, refers to "medically beneficial treatment" and clarifies that the concept of handicapped discrimination relates to decisions made solely on the basis of present or anticipated mental or physical impairments. The reference in the text of the notice and elsewhere in the rules to "present or anticipated mental or physical impairments" is based on the definition of "handicapped person" in existing regulations, 45 CFR 84.3(j). The Department believes this phrase conveys a better understanding than use of the word "handicap."

The Department has also changed the heading of the notice to eliminate what many perceived to be a negative statement. The revised notice adopts the same heading, "Principles of Treatment of Disabled Infants", adopted by the coalition of leading disability and medical organizations in their landmark statement of principles.

In seeking to compose the wording of the notice, the Department has sought to set forth a simple, understandable, and accurate description of the requirement of the law. To a significant degree, the application of section 504 in this context defies a simple and precise restatement. The wording of the notice, however, does not establish a legally mandated rule of conduct; it merely conveys information. In recognition of the impossibility of setting forth a statement that covers all possible dimensions and nuances of the statute, the notice advises that callers may obtain further information by calling the designated contact points.

The Department believes this statement resolves many of the concerns regarding ambiguity of the prior version of the notice without becoming so cumbersome and complicated that it confuses more than it informs.

Concerning other comments, the Department is not adopting the suggestion that hospitals be required to notify HHS that the notice has been posted. There are insufficient benefits accruing from establishing a mechanism for checking off approximately 7,000 unverified notifications of posting to justify the administrative burden on the Department and recipients.

In addition, consistent with the objective of targeting the notice to nurses and other medical professionals, and in view of concerns about frightening parents, the Department is not adopting the suggestion that the nondiscrimination notice be required on hospital admission or consent forms. However, the Department encourages hospitals and Infant Care Review Committees to consider seriously developing some written information for parents with respect to hospital policies and procedures in connection with this issue. Such information could include an explanation of rights and responsibilities of parents, infants, and hospitals, the operation of the ICRC, available social services, and other pertinent information.

The Department is also not adopting numerous suggestions for additions to the notice because they are unnecessary and would make the notice cumbersome and possibly confusing. Statements concerning the existence of sanctions for noncompliance, the applicability of section 504 to infants born alive after abortions, the lawfulness of withholding futile treatments, and the applicability of section 504 to a wide range of aspects of medical care are all quite correct, but their inclusion in the notice is unnecessary.

The Department is not adopting the suggestion that the notice state that callers are not required to identify themselves. Although the Department will take appropriate follow-up action on anonymous calls that convey credible and specific information, the Department does not wish to encourage callers to remain anonymous because there is great value in having the ability to recontact the complainant as the inquiry or investigation progresses. The Department believes the statements contained in the notice regarding confidentiality of the identity of callers and prohibitions against retaliation are adequate to overcome the understandable reluctance a sincere potential complainant may have.

Finally, although the statement is correct, the Department adopts the suggestion that the reference to violations of state criminal and civil laws be deleted because it is unnecessary and potentially inflammatory.

C. RESPONSIBILITIES OF CHILD PROTECTIVE SERVICES AGENCIES

A number of commenters addressed the provision of the proposed rule requiring that state child protective services agencies establish and maintain written methods of administration and procedures to ensure full utilization of their authorities pursuant to state law to prevent instances of medical neglect of handicapped infants.

Several child protective services agencies and their representatives opposed this provision. As stated by the National Council of State Public Welfare Administrators:

> While the NCSPWA agrees there is a need to establish additional protections for infants born with handicapping conditions * * * we

> believe the child protective services agency is not, as a rule, the appropriate authority to establish standards for medical treatment, to police the medical profession, or to make the kinds of medical/ethical judgments required in this area.

The State of Nebraska Department of Public Welfare expressed support for increased involvement of state child protective services agencies:

> We feel that the agency with primary responsibility for investigation and enforcement of this law should be the State Protective Services Agency. We further would suggest that hospital administration be charged with the responsibility for reporting any possible violations of this law to the State Protective Services Agency. * * * The State Protective Services Agency should be responsible for reporting to the Office of Civil Rights the results of any actions taken as a result of the report. * * *

Some commenters urged deletion of the requirement that state agencies report cases to OCR because it conflicts with the confidentiality requirements of state child abuse and neglect statutes and presents an unnecessary administrative burden. Other commenters suggested that this requirement be expanded to require reports to OCR at each step of an agency's investigation. Other commenters suggested that state child protective services agencies be required to involve state protection and advocacy systems for the developmentally disabled in all of its activities related to this issue.

Response

Section G, below, includes a discussion of the applicability of section 504 in cases where a refusal to provide medically beneficial treatment is a result, not of decisions by a health care provider, but of decisions by parents. As explained in that section, it is the responsibility of the hospital in such a case to report the circumstances to the state child protective services agency. If that agency receives Federal financial assistance in its child protective services program, it may not fail, solely on the basis of the infant's present or anticipated physical or mental impairments, to utilize its full authority pursuant to state law to protect the infant. Although there are some variations among state child protective statutes, all have the following basic elements: a requirement that health care providers report suspected cases of child abuse or neglect, including medical neglect; a mechanism for timely receipt of such reports; a process for administrative inquiry and investigation to determine the facts; and the authority and responsibility to seek an appropriate court order to remedy the apparent abuse and neglect, if it is found to exist.

Consistent with the applicability of section 504 to child protective services agencies and with the typical elements of state child protective statutes, the proposed rule included a subsection requiring that, within 60 days of the effective date, "each recipient state child protective services agency shall establish and maintain written methods of administration and procedures to assure that the agency utilizes its full authority pursuant to state law to prevent instances of medical neglect of handicapped infants."

This provision was modeled after an existing provision in the Department's regulation implementing title VI of the Civil Rights Act of 1964, 45 CFR 80.4(b), which requires all continuing state programs to have "such methods of administration for the program as are found by the responsible department official to give reasonable assurance" of compliance.

The proposed rule went on to specify several elements which must be included in the agency's methods of administration and procedures. Four of these elements precisely mirror the common fundamental components of state child protective statutes.

The proposed rule also called for immediate notification to the Department of each report of suspected medical neglect of a handicapped infant, the steps taken by the agency to investigate such report, and the agency's final disposition of such report. This requirement was also based upon an existing regulation, 45 CFR 80.6(b), which requires compliance reports "in such form and containing such information" as the Department may require. Therefore, the proposed rule's requirement for notification to OCR is simply a specification of a type of compliance report the Department deems necessary to monitor the recipient's compliance.

With respect to the comments concerning the potential conflict between this notification requirement and the confidentiality provisions of state child abuse and neglect statutes, this provision is entirely consistent with existing regulatory requirements of recipient child protective services agencies under 45 CFR 80.6(c), which includes the statement: "Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this part."

In addition, HHS regulations requiring, as a condition of receiving Federal funds, state child protective services agencies to protect the confidentiality of child abuse and neglect information also make clear that HHS and the Comptroller General of the United States must have access to documents and other records "pertinent to the HHS grant." 45 CFR 1340.14, 74.24.

The Department has not adopted the suggestion that more detailed requirements be established for state child protective services agencies because the requirements should be flexible enough to be easily incorporated into existing agency procedures.

Section 84.55(c)(1) of the final rules adopts the corresponding provision of the proposed rules without substantive change. In summary, it simply restates existing section 504 responsibilities of recipient state child protective services agencies; requires standard procedures to assure compliance (as has been long required for continuing state programs under title VI); specifies the basic elements of those procedures (which precisely mirror the standard components of state statutes); and specifies a form of compliance reports required under existing agency responsibilities. Consistent with the Department's investigative guidelines § 84.55(c)(2) encourages state agencies to involve Infant Care Review Committees in connection with the agencies' actions pursuant to its state law and procedures.

D. EXPEDITED ACCESS TO RECORDS

The final rules create a limited exception to the Department's existing regulations pertaining to access to sources of information. The existing regulation, 45 CFR 80.6(c), made applicable to section 504 cases by 45 CFR 84.61, states:

> Each recipient shall permit access by the responsible Department official or his designees during *normal business hours* to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this part. (Emphasis supplied.)

The proposed rules included a modification to specify that access to pertinent records and facilities of a recipient "shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual." The final rules adopt this change in § 84.55(d).

A number of commenters expressed support for this provision as essential to efforts to save lives. Others objected on the grounds that investigations are highly disruptive, the OCR officials are not qualified to make a judgment regarding the degree of danger to the life or health of a handicapped individual and that the rule should specify circumstances warranting access and procedures applicable to investigations after normal business hours.

Response

The Department views this as a minor, technical clarification. Access to recipient facilities and sources of information is required by existing regulations and is essential for the Department to carry out its statutory obligation to determine whether recipients are in compliance with civil rights laws. The provision in existing regulations regarding "normal business hours" is nothing more than a recognition that many recipients conduct their federally assisted programs and activities only during those hours.

The furnishing of inpatient medical services, however, is not a 9:00 a.m. to 5:00 p.m., Monday through Friday undertaking. Rather, the "normal business hours" for nurseries and neonatal intensive care units are 24 hours a day, seven days a week. The Department, therefore, has the authority to seek pertinent records at any time even in the absence of this revision. Nonetheless, the Department adopts this change to clarify its authority and recipients' obligations. The objections expressed regarding this provision are substantially the same as objections to investigative procedures generally, and are discussed in section H, below.

This modification makes clear where the circumstances indicate a risk of imminent, irrevocable harm due to suspected noncompliance, the Department will, as it must, initiate immediate action to determine compliance.

E. EXPEDITED ACTION TO EFFECT COMPLIANCE

The final rules include a slight revision to existing regulatory procedures concerning remedies for noncompliance. Existing regulations, 45 CFR 80.8(a) and (d) (made applicable to section 504 cases by 45 CFR 84.61), provide:

> If there appears to be a failure or a threatened failure to comply with this regulation . . . compliance with this part may be effected by the suspension or termination of or refusal to grant or to continue Federal financial assistance or by any other means authorized by law. Such other means may include . . . a reference to the Department of Justice with a recommendation that appropriate proceedings be brought to enforce any rights of the United States under any law of the United States . . . or any assurance or other contractual undertaking. . . .
>
> * * * * *
>
> No action to effect compliance by any other means authorized by law shall be taken until (1) the responsible Department official has determined compliance cannot be secured by voluntary means, (2) the recipient or other person has been notified of its failure to comply and of the action to be taken to effect compliance, and (3) the expiration of at least 10 days from the mailing of such notice to the recipient or other person.

The proposed rule included a provision that the normal requirement of providing 10-days notice "shall not apply when, in the judgment of the responsible Department official, immediate remedial action is necessary to protect the life or health of a handicapped individual." The final rule, in § 84.55(e), adopts this revision.

A number of commenters expressed support for this provision as essential to efforts to save lives; others objected because the rule did not identify standards for waiving the 10-day notice or alternate procedure to be followed.

Response

The Department considers this a minor, technical change. The 10-day notice was designed to facilitate pursuit of informal compliance in circumstances where noncompliance did not imminently threaten lives. The failure to provide nourishment or treatment to a handicapped infant, however, may have such a consequence.

As a matter of legal interpretation, the Department believes the normal 10-day notice rule would, even absent the proposed change, be inapplicable in a case where the government seeks a temporary restraining order to sustain the life of a handicapped infant in imminent danger of death. Such actions would often be for the purpose of preserving the status quo, such as by continuing the provision of nourishment and routine care, pending a more definitive determination of compliance or noncompliance with section 504, rather than "to effect compliance" following a determination of noncompliance. In addition, the Department believes federal judges would be appropriately loathe to allow minor procedural technicalities to defeat totally the accomplishment of the statutory purpose. Nonetheless, the Department proposed this limited exception to the normal 10-day notice rule to clarify its authorities and corresponding recipient responsibilities.

The determination of the need to waive the 10-day notice will be made in accordance with the standard investigative procedures, explained in section H, below. Concerning alternate notice procedures, the final rule provides that oral or written notice will be provided as soon as practicable.

F. GUIDELINES RELATING TO HEALTH CARE FOR HANDICAPPED INFANTS

Most of the comments submitted during the comment period dealt with issues well beyond the specific provisions of the proposed rules, such as the applicability of section 504 to this subject matter and the Department's section 504 enforcement process.

Like the proposed rules, the final rules contain four discrete requirements applicable to recipients of Federal financial assistance. First, hospitals must post an informational notice. Second, the normal 10-day notice before initiating action to effect compliance can be waived when immediate action is necessary. Third, access by the Department to pertinent records and facilities can be obtained after "normal business hours" when immediate access in necessary. Fourth, state child protective services agencies must establish procedures to utilize their full authority under state law to prevent medical neglect of handicapped infants.

To bring these specific provisions further back into focus, it is useful to note what the final rules, like the proposed rules, do *not* do. They do not establish the applicability of section 504 to the provision of health care to handicapped infants. The applicability of section 504 is already established by the statute and the existing HHS regulations. They do not establish the authority or procedures of HHS to investigate reports of suspected noncompliance with section 504. Authority and procedures are already established by the statute, existing regulations and administrative practices. They do not establish a toll-free telephone number, which has been established and is in operation. Although most of the controversy concerning the rules relates to the broader issues, the mandatory aspects of the final rules deal only with several discrete points.

Nonetheless, many of the comments relating to the broader issues were highly relevant and valuable. Other comments on the broader issues reflected a lack of understanding of how the Department interprets the applicability of section 504 in this area and the Department's compliance procedures. To clarify these issues, the final rules include an appendix, which sets forth guidelines relating to health care for handicapped infants. This appendix includes interpretative guidelines relating to the applicability of section 504 and guidelines for HHS investigations in this area. These guidelines do not independently establish rules of conduct or substantive rights and responsibilities, which are established by the statute and existing regulations. The Department will apply these guidelines flexibly to take into account the circumstances presented in each case regarding both the determination of compliance or noncompliance and the conduct of the investigation. These guidelines are set forth as an appendix to the final rules simply to assist recipients and the public in understanding the Department's general interpretations and procedures. This appendix becomes a part of the permanent Code of Federal Regulations.

G. INTERPRETATIVE GUIDELINES RELATING TO THE APPLICABILITY OF SECTION 504

Medically Beneficial Treatment

As stated in the preamble to the proposed rules, the Department interprets section 504 as requiring that medically beneficial treatment not be withheld, solely on the basis of handicap, from a handicapped infant.

Three of the questions on which the July 5 notice of proposed rulemaking specifically solicited comments concerned the issue of medically beneficial treatment as the standard to guide treatment decisions, including further explanations that would assist health care providers and the public in understanding the requirements of Section 504, implications concerning cost and the allocation of medical resources, and the impact of perceived economic, emotional and marital effects on parents.

Among commenters supporting the standard of providing medically beneficial treatment was the Down's Syndrome Congress:

> Some children may be unwanted by their parents. . . . The Down's Syndrome Congress does not seek to judge those parents who do not feel that they can adequately parent because of the handicap. Rather, we seek to make available those adoption homes that want children who have Down's syndrome.

Also typical of comments in support of the standard of providing medically beneficial treatment was the comment of the Association for Retarded Citizens:

> No quality of life or other such considerations are acceptable to the ARC. Although we are primarily a parent organization and many ARC members have had significant difficulty (financial, emotional, etc.) raising their mentally retarded child, we come down strongly on the side of the child.
>
> Available medical and other technology is not able to fully predict the future capacity of most mentally retarded children, especially in the first days and weeks of life. Our members can cite numerous examples of improper and wrong advice given to them by physicians about the future capacities of their children.

A number of commenters argued that the medically beneficial treatment standard is inappropriate. For example, the Department received the following comment from a Texas physician:

> [N]ot only is the "very strict standard" advocated by the President's Commission "not being uniformly followed," [as stated in the HHS July 5 NPRM] it is probably close to *uniformly not* being followed. The "very strict standard" the Secretary of Health and Human Services is trying to foist on the medical community is contrary to the usual practices of that community. (Emphasis in original.)

Similarly, the following comment was submitted by an Alabama physician:

> Recently I have treated a 13-month old black child who has congenital heart disease, spastic encephalopathy, vomiting, repeated bouts of bilateral pneumonia, internal squint of the left eye, and mental deficiency. He is one of the thousands of children who are the victims of the neonatal intensive care units located in every medical center. He was born premature, weighing two pounds and ten ounces. With modern treatment and instruments he survived. These children have no future and are a terrible burden on their parents and this nation.
>
> * * * What good is it treating these premature babies? Will it not be better if they are left to die? * * * We are compounding our problems by bringing into life thousands of congenitally sick babies which nature has rejected.

A number of commenters, particularly medical organizations, suggested different articulations of standards. For example, the American Medical Association combines a number of notions in articulating the standard to be applied, including consideration of "quality of life", and deference to parental decisions unless there is "convincing evidence to the contrary." The full text of the AMA position is as follows:

> QUALITY OF LIFE. In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, witholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued. In desperate situations involving newborns, the advice and judgment of the physician should be readily available but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.

Another articulation of standards, submitted by the Biomedical Ethics Committee of the University of Minnesota Hospitals, includes the following ethical principles:

> When the burden of treatment lacks compensating benefit or treatment is futile, the parent(s) and attending physician need not continue or pursue it.
>
> Therapies lack compensating benefit when: (a) they serve merely to prolong the dying process; (b) the infant suffers from intolerable, intractable pain, which cannot be alleviated by medical treatment; (c) the infant will be unable to participate even minimally in human experience.

Probably the most poignant comments regarding the standard which should be applied relating to the provision of medical care to handicapped infants were submitted by parents of handicapped children. Of 100 commenters who identified themselves as parents of handicapped persons, 95 supported the proposed rule and five opposed it. From a Montana mother:

> My daughter Keough was born in November 1980 with Down's syndrome and a host of birth defects in her digestive system similar to Baby Doe's problems * * * Twenty minutes after her birth our then pediatrician offered to let her starve in the hospital nursery * * *

* * * * *

> * * * There are times when I am getting up for the tenth time during the night to suction my daughter's trach tube so she can breathe that I would give anything not to have to deal with the situation, but I will never regret having her as part of the family.

From a mother and father, both physicians, in California:

> [A]s the parents of an eight-year-old boy with Down's Syndrome, who suffers from marked retardation and a severe cardio-pulmonary condition, we do appreciate both the deep anguish and the countless joys that derive from caring for and caring about a

> severely handicapped child. There is no limit set on the strength, the growth and the fulfillment that his love continues to bring us every day For his sake and for the sake of all the handicapped newborn, it is urgent that safeguards be enacted. Let merciful caring, not mercy-killing, be our answer to their needs.

Another dimension of the comments concerning the interpretation of section 504 as requiring that medically beneficial treatment not be withheld solely on the basis of handicap relates to the difficulty of determining the "medically beneficial treatment." As stated by the Children's Hospital of Boston:

> [The NPRM] states that the denial of treatment where there is no medical benefit to the individual would not be discriminatory because the individual would not be a "qualified handicapped person" within the meaning of section 504. . [A problem with this analysis is that] it relies on outcome which cannot always be predicted or, even if predicted is not always accurate, may be affected by other factors, and may not even be known for an indeterminate time. If section 504 is to provide guidance in treatment situations, its applicability should be known at the outset. Otherwise staff will be subjected to an after-the-fact scrutiny which may well be inaccurate and oppressive.

Another comment regarding the role of medical judgements was submitted by presiding Judge John G. Baker, Monroe Superior Court, Division III, the Judge who decided the Bloomingtom Infant Doe case:

> The question in the Infant Doe case was, when parents are confronted with two competent medical opinions, one suggesting that corrective surgery may be appropriate and the other suggesting that corrective surgery and extraordinary measures would only be futile acts, does the law allow the parents to select which medical course to follow? It was the decision of the Indiana Court that the law provided the parents with the responsibility of choosing which medical course to follow without governmental intervention.

Response

The Department's position remains unchanged. Section 504 provides:

> No otherwise qualified handicapped individual shall, solely by reason of his handicap, be excluded from participation, be denied the benefits of, or be subject to discrimination under any program or activity receiving Federal financial assistance. .

The statute defines a "handicapped individual" as:

> Any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, or (iii) is regarded as having such an impairment.

A key issue in applying section 504 in any context is that the handicapped individual who is allegedly excluded from participation in, denied the benefits of, or subject to discrimination under a federally assisted program or activity be "otherwise qualified" to participate in, or benefit from, the program or activity, in spite of his or her handicap. In the context of receiving medical care, the ability to benefit for a handicapped person is the ability to benefit medically from treatment or services. If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's present or anticipated physical or mental impairments, the individual is "otherwise qualified" to receive that treatment or service, and it may not be denied solely on the basis of the handicap.

Therefore, the analytical framework under the statute for applying section 504 in the context of health care for handicapped infants is that health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.

Not only is this analytical framework directed by the statute, the Department believes the medically beneficial treatment standard is the appropriate guiding principle for providing health care services to handicapped infants. The Department agrees with the President's Commission that "it is all too easy to undervalue the lives of handicapped infants," and that it is "imperative to counteract this" by excluding "consideration of the negative effects of an impaired child's life on other persons" and to treat handicapped infants "no less vigorously than their healthy peers."

The Department also agrees with the essential principle contained in the joint statement of November 29, 1983, by the coalition of medical groups and disability organizations, including the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, the association for Retarded Citizens, the Spina Bifida Association of America, and others:

> When medical care is clearly beneficial, it should always be provided. . . . The individual's medical condition should be the sole focus of the decision.

Consistent with the recommendations of the President's Commission and the principles agreed to by the coalition of medical and disability groups, paragraphs (1), (2) and (3) of section (a) of the appendix state the basic interpretative guidelines of the Department for applying section 504 in this context. These interpretative guidelines make clear that health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant, who, in spite of such impairments, will medically benefit from the treatment or nourishment. They also made clear that futile treatments or treatments that will do no more than temporarily prolong the act of dying of a terminally ill infant are not required by section 504, and that, in determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected. The principle of respecting reasonable medical judgments reflects the Department's recognition that in many cases the process of medical decisionmaking is not mechanical and precise. Analyses of medical risks, medical benefits, possible outcomes, complications, and the like require experience and judgments. Most of all, they must be specifically based on the actual circumstances presented in any given case. The statutory framework does not provide for, nor will the Department seek to engage in, second-guessing of reasonable medical judgments regarding medically beneficial care.

The principle of respecting reasonable medical judgments in the context of applying section 504 is also consistent with analogous case law. For example, the Supreme Court has made it clear that the application of constitutional protections do not interfere with *bona fide* medical judgments so as to authorize a court "to specify which of several professionally acceptable [treatment] choices should have been made." *Youngberg* v. *Romeo,* 457 U.S. 307, 321 (1982).

However, the Department also recognizes that not every opinion expressed by a doctor automatically qualifies as a reasonable medical judgment. For example, a doctor's opinion that available corrective surgery to save the life of a Down's syndrome infant should be withheld is contrary to the opinion of the President's Commission and comments submitted to the Department by the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, and other medical organizations. It is not within the bounds of reasonable medical judgment and is not entitled to deference.

Parental Decisions

A number of commenters argued that the Department's analysis of section 504's applicability fails to take into account the lack of authority hospitals and physicians have to perform treatment to which the parents have not consented. Some commenters expressed a belief that the Department purports to require physicians and hospitals unilaterally to overrule parental decisions. As stated by the American Medical Association:

> If section 504 is applied as the Department claims it should be, physicians and hospitals will be required to treat a handicapped infant in all cases, regardless of parental consent, for fear of sanctions allegedly authorized by section 504.

Similarly, the National Assosciation of Children's Hospitals and Related Institutions stated:

> Nor does the rule recognize that, in lieu of indications to the contrary, decisions of care of the infant made by these parents, based on their determination of the child's best interest, are theirs to make, a right and responsibility assigned to them universally by state statute. . . .

Also in connection with the issue of a recipient's section 504 responsibilities in cases where parents refuse to consent to medically beneficial treatment, a number of commenters criticized a statement included in the Department's May 18 notice to health care providers that:

> Health Care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

The criticism was that to discharge the infant, as the statement implied the hospital should do, would be unlikely to advance the objective of assuring that the infant receive medically beneficial treatment.

Response

The Department's position has been, and continues to be, that the lack of parental consent does have an impact on a recipient hospital's section 504 responsibilities, but that the lack of parental consent to provide particular treatment does not remove from hospitals the obligation to operate other aspects of their program without discrimination.

Although the need may not arise frequently, it is an accepted part of the operation of hospitals to contest the denial of parental consent when such a decision is not in the best interest of a child. Most hospitals have established procedures to petition courts to order medical care when parents do not provide consent for treatment that is medically needed and appropriate.

In addition to the internal hospital procedures, state laws generally establish responsibilities of health care professionals where treatment is being withheld because of improper denial of parental consent. Health care professionals are generally required by state law to report cases of abuse, neglect, or other threats to a child's health. These laws, whether explicitly or implicitly, include the denial of needed medical treatment as an event requiring reporting.

The requirement that health care providers report instances of improper denial of medical care is no less a part of their program than is the provision of care itself. Both arise from the recipients's program of administering to the medical interests of its patients. Section 504 prohibits discrimination on the basis of handicap in the operation of federally assisted programs and activities. Thus, a recipient that, as a matter of practice or law, reports to State authorities the withholding of needed medical treatment from an infant may not deny the same service or benefit to a qualified handicapped infant because the infant is handicapped.

Section 504 applies only to programs or activities receiving federal financial assistance; it does not apply to decisions made by parents. Where a non-treatment decision, no matter how discriminatory, is made by parents, rather than by the hospital, section 504 does not mandate that the hospital unilaterally overrule the parental decision and provide treatment notwithstanding the lack of consent. But it does require that recipient hospitals not fail, on the basis of handicap, to report the apparently improper parental decision to the appropriate State authorities, or to seek judicial review itself, so as to trigger the system provided by State law to determine whether the parental decision should be honored. Action by hospitals to seek judicial review is not uncommon in cases where, for example, parents have objected on religious grounds to a medically necessary blood transfusion for their child.

The Department agrees with the criticism of the sentence in the May 18, 1982 notice. This statement reflected a recognition by the Department that section 504 does not require hospitals unilaterally to overrule parental decisions, and that hospitals cannot provide treatment without parental consent. The point should have been better stated that a recipient hospital may not blindly implement improper and discriminatory parental decisions. Rather, the hospital should resort to the system provided by state law to determine whether a parental decision should be implemented.

Therefore, the proper analysis of the applicability of section 504 in cases where the failure to provide medically indicated treatment is due to a lack of parental consent is that a recipient hospital is not required to seek to unilaterally overrule the parents, but it must adhere to the standard practice, as required by state law, to make a report to the state agency charged under state law with responsibility to initiate the determination as to whether the parental decision was proper, or to seek judicial review itself. This interpretative guideline is set forth in section (a)(4) of the appendix.

Rather than representing an improper Federal government attempt to "question and overturn the decisions of parents concerning their children's medical treatment," the Department is simply requiring that the long-standing requirements and mechanisms of *state* law for defining the limits of parental authority not be rendered, through discriminatory actions of recipient hospitals, *de facto* inoperative.

Examples

The July 5 proposed rule was accompanied by an appendix explaining the manner in which section 504 applies to the provision of health care services to handicapped infants and providing several examples of its applicability to particular factual situations. A number of commenters criticized statements contained in that appendix. Criticisms and comments were as follows: (a) Use of phrases such as "futile therapies", "services generally provided", and "dubious medical benefit" are ambiguous. (b) The characterization of the infants with intracranial hemorrhage as analogous to anencephaly is incorrect. Intracranial hemorrhages vary greatly in severity, and are generally treatable and treated. (c) The American Society for Parenteral and Enteral Nutrition stated that although there are no circumstances justifying "withholding oral feeding through a working digestive tract in any patient capable of digesting food, in whole or in part," there may be "limited circumstances" in which not providing nourishment through intravenous means "may be appropriate." (d) The appendix does not indicate the appropriate care for infants who have conditions with prognoses worse than Down's syndrome but less severe than anencephaly, such as Trisomy 18, Trisomy 13, Holoprosencephaly, Hydranencephaly, Cornelia de Lange Syndrome, and many others.

(e) "It would be impossible to develop a complete list of handicaps to which the regulations apply. The limited ability to predict outcomes, and the rapid changes in diagnostic and therapeutic modalities make such a goal wholly impracticable."

Response

The application of constitutional and statutory civil rights protections in scores of contexts is difficult. A glance at the Supreme Court's docket confirms this, as every year difficult issues are presented to the Court for resolution. These cases often produce split decisions and multiple opinions.

Therefore, it is to be expected that definitive statements on various dimensions of the applicability of the handicapped discrimination law in connection with health care for handicapped infants, a subject no less difficult than many other aspects of civil rights law, would be few. The imprudence of seeking to speculate on the outcome of applying section 504 in a wide variety of specific factual circumstances was underscored by some of the comments received.

Keeping in mind the utility of providing some examples to assist in understanding the analytical framework of the statute, but also the need to allow individualized attention to specific factual circumstances, the guidelines included in the appendix (section (a)(5)) set forth examples dealing with Down's syndrome, spina bifida, anencephaly, and extreme prematurity.

The Department agrees with the comment that it would be impossible to establish a specific list of all handicapping conditions and the proper treatment in each case. None of the commenters who perceived ambiguities had convincing answers to the questions they raised.

It is appropriate that the law (and thus the government) does not prospectively and unequivocally answer every hypothetical question. In many cases, the law, like medical treatment, can only be applied on a case-by-case basis with a full appreciation for the facts presented.

But it is also appropriate that the law and government have an analytical framework for approaching the issue and a procedural framework for seeking, in cooperation with the medical community and advocacy groups, to narrow the "gray area." The final rules seek to do no more, and importantly, no less.

H. GUIDELINES FOR HHS INVESTIGATIONS RELATING TO HEALTH CARE FOR HANDICAPPED INFANTS

Conduct of Investigations

The July 5 notice of proposed rulemaking solicited comments on HHS investigative procedures. A number of commenters argued that OCR complaint investigations are highly disruptive. The primary concerns expressed in this regard were:

(a) Due to the complexity of the subject matter, there are many erroneous complaints, either by well-intentioned, but ill-informed, persons or by disgruntled employees.

(b) Anonymous calls are not reliable.

(c) Investigations monopolize the time of physicians, nurses and other hospital staff, and make medical records, while under review by OCR investigators, unavailable.

(d) Investigations carry with them the potential for sensational media coverage, which can unjustly damage the good reputations of parents, hospitals and health care professionals.

(e) The presence of OCR investigators is likely to frighten other infants' parents who will assume that, because investigators are present, the hospital must be guilty of improper conduct.

Response

Although some potential for inconvenience or disruption exists in connection with any type of law enforcement investigation, because of the traumatic circumstances of an infant's illness, the potential for sensationalistic media coverage, and other factors, the Department is very sensitive to the special nature of "Infant Doe" investigations. As HHS has gained experience in conducting these investigations, revisions to investigative procedures have been implemented to minimize any disruptive effects. It is the policy of the Department to do everything possible, consistent with its statutory obligation to investigate effectively all complaints of violations of section 504, to minimize any disruptions that may be caused by OCR investigations.

OCR has made adjustments to investigative procedures. It now undertakes a careful screening of complaints in an effort to avoid unnecessary on-site investigations. This screening consists of immediately initiating a preliminary inquiry with the hospital to obtain information regarding the infant in question. The information initially received from the complainant and that received from the hospital is then evaluated to determine whether there is a need for an on-site investigation. Particular factors taken into account are the source of the complainant's information (first-hand knowledge, overheard a discussion, etc.), the complainant's position to have reliable information (a nurse in the ward where the infant is being treated, a friend of a friend, etc.), the specificity of the information provided by the complainant and hospital, whether there is any indication of a lack of parental consent for the provision of all medically beneficial treatment, the analysis of the ICRC, whether the hospital is cooperative in connection with the inquiry, and other pertinent factors.

None of these factors considered in evaluating the information provided by the complainant and the hospital is, by itself, determinative. For example, the Department prefers that the complainant provide his or her name. Not only does it corroborate that the complainant takes the matter seriously and reflects some degree of confidence the complainant has in the accuracy of the information being conveyed, having the complainant's name also permits follow-up communications to seek clarification of the information gathered. However, the Department recognizes that a complainant may not be willing to provide his or her name due to fear of retaliation, and that anonymity does not necessarily suggest that the complaint is not valid, particularly if the specificity of the information provided and other factors support the credibility of the complaint. Therefore, the determination as to whether an on-site investigation is needed is made on the totality of the information available to OCR from the complainant, the hospital, and any other source consulted (such as an OCR medical consultant and the state child protective services agency).

HHS believes this procedure, if hospitals cooperate in its implementation, can avoid unnecessary on-site investigations, which inherently have a potential for some inconvenience. Although hospital officials may be properly reluctant to provide information over the telephone, they can confirm the credentials of the OCR investigator making the telephone contact by calling the toll-free telephone number to verify that the caller is, in fact, an OCR investigator.

Where, as a result of this preliminary inquiry, there appears to be no need for an immediate on-site investigation, none will be conducted. However, to assure that HHS is adequately meeting its statutory responsibility, where there is a significant question as to compliance with section 504, doubt will be resolved in favor of initiating an on-site investigation.

This preliminary inquiry process is undertaken by OCR in an effort to accommodate the special circumstances presented in connection with "Infant Doe" complaints. This procedure should not be construed as suggesting that the Department believes there are any limitations to its legal authority to investigate all complaints or to otherwise collect information regarding recipient compliance in accordance with the Department's existing section 504 regulations. Nor does this preliminary inquiry process establish any legally enforceable procedural right or precondition to the conduct of on-site investigations.

When on-site investigations are conducted, OCR's procedures minimize any potential inconvenience or disruption. Every effort is made, consistent with the need to obtain prompt information, to accommodate the busy schedules of health care professionals to avoid diverting them from their important duties. Similarly, OCR has never had a problem working out access to medical records to avoid their being unavailable to health care professionals who also need access to them.

With respect to media interest, OCR has a firm policy of providing no comment to the press on the details of any open investigation. HHS believes organizations or individual complainants concerned about proper patient care should be extremely sensitive to threats to proper care inherent in making premature and unsupported comments to the media. Similarly, the media should be attentive to OCR's admonition, regularly given in response to media questions, that the fact that an investigation is being conducted does not imply that an allegation is true.

Section (b)(1) through (5) of the appendix spell out the basic guidelines, including the preliminary inquiry process, applicable to HHS investigations in this area. These guidelines make specific reference to the role of Infant Care Review Committees. Whenever a hospital has an ICRC, established and operated substantially in accordance with the suggested model, the Department will consult closely with the ICRC in connection with a preliminary inquiry or investigation and will give careful consideration to the analysis and recommendations of the ICRC.

The Department believes OCR procedures, including the initial inquiry process, minimize the potential for disruption. HHS will, on the basis of further experience gained, such as with ICRCS, continue to evaluate its procedures consistent with the policy of effective enforcement with a minimum of disruption. The Department also notes that there is probably an irreducible level of inconvenience associated with any effort to provide safeguards to prevent the fatal consequences of discriminatory decisions. It must be recognized, however, that the risks of a certain amount of inconvenience or disruption are significantly preferable to the risks of tragic loss of life due to discriminatory decisionmaking.

Use of Medical Consultants

Another concern expressed by commenters relates to the qualifications of the individuals involved in the administrative fact finding process to evaluate correctly the medical circumstances present in any particular case. For example:

> The Alabama Hospital Association strongly feels that the [investigative] team should be comprised of highly trained and licensed medical personnel. Under no circumstances should anyone less than licensed medical personnel be allowed to intrude in this area of medical decisionmaking and impose alternative judgments or conclusions.

The Spina Bifida Association of America made a similar comment from a different perspective:

> The key to effective enforcement is securing an independent medical examination of children allegedly being denied treatment, by a physician or medical team both skilled in modern treatment techniques *and* committed to the equal treatment principle. Such physicians do exist, particularly at expertise centers that have specialized in the care of children with spina bifida. The only way to ensure effective enforcement is to give disability rights groups like SBAA the ability to recommend *which* expertise centers and expert consultants are used by the regional OCR offices to conduct the independent medical examinations.

Response

HHS agrees that OCR investigators do not have the medical expertise to make independent judgements concerning difficult medical issues. For this reason, the Office for Civil Rights has made arrangements with qualified physicians to serve as medical consultants to OCR in "Infant Doe" investigations. This process is noted in section(b)(6) of the appendix.

The role of the OCR medical consultants is to provide OCR with an analysis of the medical issues present in any particular case, and an opinion as to whether medically beneficial treatment was provided. Based on this analysis, OCR makes a determination as to whether any medically beneficial treatment may have been discriminatorily denied solely on the basis of the infant's handicap.

The extent of the involvement of the OCR medical consultant has varied depending upon the circumstances of particular cases. In all cases the OCR medical consultant reviews the pertinent medical records. In some cases the OCR medical consultant and the attending physician have discussed a case by telephone. HHS believes the experience to date with OCR medical consultants demonstrates the effectiveness of their involvement. HHS is aware of no case in which a recipient has challenged the quality of the medical consultant's evaluation or the OCR findings based upon it.

It is important that all interested groups understand the precise and limited role of the OCR medical consultants. Their function is *not* to take over the medical management of particular cases, to conduct a personal, independent examination of the infant, to make independent treatment recommendations to parents, or to otherwise engage in any direct practice of medicine concerning the infant.

The Department has no authority to compel unilaterally an independent medical examination of a child who is the subject of a section 504 complaint. Under applicable requirements of law, physicians may not practice medicine on an infant patient without the consent of the parents or an order of a court of competent jurisdiction.

In any given case, any of a wide variety of circumstances may be present regarding the actions of parents and health care providers. Regardless of the circumstances, the first step is to determine the facts. Only if the facts demonstrate that there is a need for governmental action can that action be pursued. A court will only issue an order if there is a showing of a need for the order, such as evidence that the hospital *is* out of compliance with section 504 or showing that the parents *are* medically neglecting the infant. Such a showing cannot be made on the basis of the bare allegations of a complaint or without a determination of the facts.

OCR's function in an investigation is to determine the facts, and the function of the medical consultant is to assist OCR in this effort. The process of determining the facts typically involves a review of medical records and discussions with health care providers involved. The OCR medical consultants assist in this process by providing identification and expert analysis of the medical issues involved. These consultants do not, and may not under applicable law, take over the medical management of the case.

With respect to the suggestion that HHS give disability groups the opportunity to recommend qualified physicians to serve as OCR medical consultants, the Department would welcome such suggestions from all interested groups.

The Department is unable to commit itself to having a medical consultant participate in person in every on-site investigation. However, the guidelines contained in the appendix state that, to the extent practicable, the OCR medical consultant will discuss the case with the hospital's ICRC or appropriate medical personnel by telephone.

Prompt Report of Investigative Findings

Another complaint made by a number of commenters regarding OCR enforcement procedures concerns the sometimes lengthy delay between completion of the on-site investigation and receipt by the hospital of notification of the outcome of the investigation. Commenters expressed concern that, particularly in connection with investigations that may have attracted local media attention, where the OCR investigation found no evidence of a violation, the hospital should have the ability to reassure the public promptly that it was involved in no improper activity.

Response

The point is well taken. Office for Civil Rights procedures pertaining to all investigations require that before the office makes an official finding, whether it is of compliance or noncompliance, a thorough record is compiled and reviewed by supervisory officials. Experience in connection with "Infant Doe" cases is that formal findings have been made in less time than is typical in connection with other civil rights investigations. However, there is generally a need for careful review by an OCR medical consultant, an HHS attorney, and supervisory officials.

The Department recognizes that there are special circumstances in connection with Infant Doe cases, and is instituting a special notification to recipient hospitals in cases where an emergency on-site investigation has been conducted. As a matter of practice, on-site investigation of complaints alleging that an infant's life is in peril due to the discriminatory withholding of medically beneficial care are conducted immediately for the primary purpose of determining whether there is a need to ask the Department of Justice to seek immediate injunctive relief to compel compliance with section 504. Generally, during the course of the investigation, when sufficient information has been obtained and discussed with the OCR medical consultant, a decision is made on whether there is such a need.

The new procedure is that, when a decision is made that there is no need to make an immediate referral to the Justice Department, the recipient hospital will be immediately notified of that decision. The investigator will, if still on-site, personally notify hospital officials. A letter to the same effect will then promptly be sent by OCR. This letter will notify the recipient hospital of the decision made concerning immediate referral to the Justice Department. It will not provide a formal finding concerning the investigation, which cannot be made until all information is analyzed and reviewed. (It may be, for example, that, although there is no emergency requiring immediate legal action by the Justice Department, there is, or was, noncompliance.)

The Department believes this immediate notification procedure, stated in section (b)(7) of the appendix, will provide a basis for the hospital to assure the press and public that OCR's initial conclusion in connection with the investigation is that no infant is in imminent peril due to discriminatory withholding of medically beneficial treatment.

Confidentiality of Records

A number of commenters criticized the enforcement process on the grounds that it infringes on the confidentiality of the physician-parent relationship and the privacy of medical records. Some of these commenters referred to the confidentiality requirements of state law and professional ethical standards.

As stated by the Federation of American Hospitals:

> The physician may be required to inform the parents that anything they may say or decide must be disclosed to federal or state authorities if an investigation results. [P]arents will find that they have a choice between sharing vital information and counseling with their physician and having their thoughts and emotions revealed to a stranger or, alternatively, withholding information.

A suggestion for an additional confidentiality safeguard, submitted by the director of nursing of a Butte, Montana hospital, was to limit review of records to one investigator, on-site, with no copies made.

Response

HHS believes there is no sound legal basis to challenge the Department's right to access to medical records for the purpose of determining compliance with section 504, and that adequate safeguards exist to protect the confidentiality of records obtained by OCR in the course of civil rights investigations.

With respect to legal authority, a state law, such as one restricting access to certain records, cannot, under the Supremacy Clause of the United States Constitution, be used to prevent accomplishment of the full congressional purpose of a Federal law. Similarly, standards of particular professional groups may not frustrate or defeat a Federal statutory duty.

Section 504 establishes certain responsibilities of recipients and authorizes and directs Federal agencies to enforce the law. Existing regulations, 45 CFR 80.6(c) (made applicable to section 504 by 45 CFR 84.61), require:

> Each recipient shall permit access by the responsible Department official or his designee during normal business hours to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this Part. . . . Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this Part. Information of a confidential nature obtained in connection with compliance evaluation or enforcement shall not be disclosed except where necessary in formal enforcement proceedings or where otherwise required by law.

The requirement that recipients provide access to records necessary to determine compliance is essential to accomplishment of the congressional purpose in enacting section 504.

HHS has adequate safeguards to protect the confidentiality of medical records obtained during the course of a section 504 investigation. In addition to the regulatory provision (quoted above) protecting confidentiality, OCR does not release confidential information in connection with any Freedom of Information Act request. Nondisclosure is permitted under that Act for records, the release of which would consititute a clearly unwarranted invasion of personal privacy. As further protection, OCR permits deletion of the patient's and parents' names and other indentifying information to the extent deletion will not impede OCR's ability to determine compliance.

The argument that the possibility that investigators will seek access to a medical file will cause parents to withhold vital information from the infant's physician is not persuasive. Courts and legislatures have repeatedly rejected arguments that exceptions to the principle of confidentiality of medical records and the physician-patient privilege would result in the withholding of information necessary to facilitate proper treatment. There are many established exceptions in the law to the principle of doctor-patient confidentiality in connection with criminal and civil proceedings where the effective administration of justice requires access to information in medical records or provided to physicians. It is also noteworthy in this regard that the Federal Rules of Evidence do not include an express doctor-patient privilege.

With respect to the suggestions for additional safeguards submitted by a commenter, OCR has in some cases been able to limit review of records to one individual at the hospital, without the need to obtain copies. However, no assurances can be made that OCR can meet its responsibility to conduct a thorough investigation under these conditions. Also, in many cases it may be preferable for the hospital to send OCR the pertinent records (with identifying information deleted), perhaps avoiding the need for any on-site investigation.

IV. Related HHS Activities

HHS has undertaken several other initiatives in cooperation with the medical community and disability organizations to improve the delivery of health care services to handicapped infants. Recently, a contact was awarded by the Office of Human Development Services, HHS to the John F. Kennedy Institute in Baltimore to develop a model for a working nationwide referral network for the developmentally disabled. Such a network, using today's sophisticated technology, will make it possible for the physician, parents, or care-takers of a developmentally disabled individual to query a single source for information about that disability and pinpoint the best or most appropriate places to get help any where in the country for that individual.

Under the terms of this award, the strong features of two important information systems are to be combined and regionalized. One is a data retrieval system for the particular use of practicing physicians. The other is accessible by the general public. The data base for the physician oriented system was developed by the Kennedy Institute in Baltimore, using data supplied by the 38 HHS supported university-affiliated facilities around the country. The American Medical Association has a contract with the Kennedy Institute to include the Institute's data as an additional offering of the A.M.A.'s nationwide medical information network, or "MINET." It is available to every "MINET" subscriber who has a desk-top computer and a telephone.

This enterprise pulls together government, the private nonprofit sector, and organized medicine, in this case, the A.M.A., to make information available to physicians concerning access to specialized care for their patients and as well as to a broad variety of support services in the community.

The more consumer-oriented data system is now functioning in South Carolina to benefit the citizens of that state. The system carries information on access to care and community support services within the state. Any individual or family member can gain access to the system merely by dialing a toll-free "800" number.

The Kennedy Institute has an excellent concept of how such a network will function. Under the contract recently awarded, it is hoped the South Carolina Model will be expanded to seven other states in the region. The next step should then be to extend the system nationally and thus make available to all citizens the best information and the most appropriate resources relative to handicapping conditions.

The availability of such a resource should do much to take the insecurity out of one effort to rally support services for the handicapped newborn.

In addition to this nationwide referral network, HHS and the Department of Education, in cooperation with the coalition of medical and disability organizations who signed the "Principles of Treatment of Disabled Infants," are organizing an effort to develop teaching models for health care professionals on improving infant care, aiding the decision-making process and use of the nationwide referral network.

The Department believes that informational and educational efforts of this kind are also of great importance in advancing the principles underlying the final rules.

V. Additional Analysis of Comments

Section III above includes an explanation of the provisions of the final rules, including an analysis of pertinent comments submitted to the Department during the comment period on the proposed rules. This section is an analysis of other comments not directly related to specific provisions of the final rules.

A. LEGAL ISSUES

A significant number of commenters addressed legal issues relating to the application of section 504 to matters concerning health care for handicapped infants.

Statutory Construction of Section 504

A number of commenters argued that, as a matter of statutory construction, section 504 of the Rehabilitation Act of 1973 is inapplicable to matters concerning health care for handicapped infants. The arguments advanced by these commenters were:

(a) The statute does not specifically mention handicapped infants, and the statutory definition of "handicapped individual" should be construed as inapplicable to infants because its reference to substantial limitations on major life activities has no application to infants since all infants are dependent on the efforts of others for performance of all external life activities.

(b) The legislative history makes no mention of handicapped infants and indicates that the primary focus of Congress in enacting the Rehabilitation Act was matters relating to vocational rehabilitation, rather than medical matters; and although the statutory definition of handicapped individual was amended in 1974 to broaden its scope beyond vocational rehabilitation, including access to services such as medical care, there was no indication that the statute, as amended, was intended to cover medical judgments about the type of treatment given any handicapped individual. As stated by one commenter:

> There is not even a hint in the legislative history of the Act or its amendments that would indicate Congressional intent to apply section 504 to medical treatment of severely handicapped infants. Rather, it is clear that Congress intended the Act to foster fruitful and independent living for handicapped individuals.

(c) The rulemaking history of the Department's section 504 regulations reveals previous HHS interpretations that section 504 is inapplicable.

Response

The Department's position remains unchanged. Section 504 clearly applies to matters concerning the provision of health care to handicapped infants, and nothing in the legislative history of the statute or rulemaking history of the

Department's regulations suggests a credible interpretation to the contrary.

Section 504 provides:

> No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . .

The statute defines a "handicapped individual" as

> any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, . . . or (iii) is regarded as having such an impairment.

An infant is a person. If an infant has a physical or mental impairment which substantially limits major life activities, or is regarded as having such an impairment, the infant is a "handicapped individual" within the meaning of the law. If a hospital engages in a program or activity which provides medical services to infants and if that program or activity receives Federal financial assistance, it is a "program or activity receiving Federal financial assistance" within the meaning of the law.

If an infant who is a "handicapped individual" is "otherwise qualified" to receive the benefits of a medical services program or activity receiving Federal financial assistance, and is denied, solely by reason of his handicap, the benefits of those medical services, that infant is within the protection of section 504.

A key issue, therefore, in applying section 504 in any context is that the handicapped individual who was allegedly excluded from participation in, denied the benefit of, or subjected to discrimination under, a federally assisted program or activity be "otherwise qualified" to participate in, or benefit from, the program or activity. To be "otherwise qualified," the handicapped individual must, in spite of his or her present or anticipated physical or mental impairment, be able to meet the essential requirements for participation in the program or activity.

In the context of receiving medical care, the ability to benefit for a handicapped person is the ability to benefit medically from treatment or services. If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's handicap, the individual is "otherwise qualified" to receive that treatment or service, and it may not be denied solely on the basis of the handicap.

Therefore, the analytical framework under the statute for applying section 504 in the context of health care for handicapped infants is that medically beneficial treatment and services not be withheld from a handicapped infant solely on the basis of the handicap.

The legislative history makes clear that by enacting section 504 Congress intended to eliminate all of the "many forms of potential discrimination" against handicapped people through "the establishment of a broad governmental policy." S. Rep. No. 1297, 93d Cong., 2d Sess. 38 (1974). The statute applies to all federally funded programs or activities, specifically including those that provide "health services." *Id.*

The rulemaking history related to the 1977 promulgation of the Department's section 504 regulations explained that the Department was not seeking to regulate with respect to the highly controversial issue of the rights of institutionalized persons to receive treatment for the condition which led to their institutionalization. Additionally, the regulation specifies that the provision of health care services generally to handicapped persons is a matter covered by the Act and the Department's rules. 45 CFR 84.52.

It is difficult to understand the theory of statutory construction that would distinguish the provision of health care services to qualified handicapped infants from the provision of other federally assisted benefits and services to qualified handicapped individuals.

The Department cannot subscribe to the theory that the definition of "handicapped individual" should be construed as inapplicable to infants because infants are dependent upon others for all major life activities. This argument appears to be based on a much too narrow view of what constitutes "major life activities." The Department's section 504 regulations define "major life activities" at 45 CFR 84.3 (j)(2)(ii), as: "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." Infants undertake at least some of these major life activities from the moment of birth.

Moreover, if this is the theory, the Department is unaware of the basis to be used in determining at what age the protections of section 504 would begin to apply.

In summary, the Department can find no clue in any bit of legal analysis or rational policy analysis to commend the notion that there is or should be a distinction in the application of section 504 based on the age of the handicapped individual.

It appears the real basis for the contention that section 504 is inapplicable in this context is that medical care is involved, rather than what some may perceive as much less complicated matters like distributing welfare benefits, developing transportation systems, administering housing programs, delivering social services, providing educational services, making employment decisions, and the like.

The Department agrees that matters relating to the provision of medical care are in some ways different from other aspects of applying section 504. For one thing, the consequences of discriminatory treatment may be much higher—a matter of life and death. Also, the analysis involved in determining whether discrimination exists may, in some cases, be much more subtle and difficult. But one aspect that appears the same in all applications of section 504 is that decisions regarding whether handicapped persons will receive the services and benefits of programs and activities receiving Federal financial assistance are sometimes made, not on the basis of the individual's actual qualifications for, and ability to benefit from, those activities, but rather on stereotypes and prejudices concerning the limitations on major life activities faced by handicapped persons. Section 504 was enacted to eliminate these considerations from such decisions. And although the section 504 analysis may be more subtle (at least in some cases), it is an anomalous and bizarre theory that section 504 can properly be used to require that a ramp be built in a hospital to assure that handicapped persons not be denied access to medical services solely on the basis of their handicaps, but that statute may not properly be used to prevent the intentional act of allowing other handicapped persons to die in that hospital, solely because of their handicaps. The Department cannot subscribe to this theory.

In summary, the Department's position is unchanged. Section 504 clearly applies to the provision of health care for handicapped infants.

Separating the "Handicap" from the Condition Requiring Treatment

A number of commenters expressed views that the section 504 analysis summarized above is incapable of application in many or most cases because the handicapping condition and the condition requiring treatment are one and the same. This fact, the commentors argue, results in an inability to separate "medical judgments" from judgments relating to social, emotional, economic, or other non-medical issues concerning which unreasonable prejudices have often caused discrimination against handicapped individuals.

Response

Although perhaps subtle, the analysis required by the statutory framework is just as applicable in a case where the handicapping condition and the condition requiring treatment are the same as it is to the "simpler" case where two distinct conditions are involved.

In the "simple" case involving two distinct conditions, such as Down's syndrome and an intestinal obstruction, the Down' syndrome does not present a medical contraindication to surgical correction of the intestinal obstruction. There is no valid medical reason (assuming no other condications) for treating the Down's syndrome infant differently than an infant with the same intestinal obstruction and no Down's syndrome.

The same analysis applies where the handicapping condition and the condition to be treated are the same. In such a case the "handicap" is the physical or mental impairment the infant has or will have (or "is regarded as having") *after* completion of the treatment under consideration. In the case of an infant born with myelomeningocele, for example, the treatment which must be considered is surgery to close the protruding sac to prevent infection and other potentially fatal consequences. The "handicap" is the physical and/or mental impairment the infant is regarded as likely to have in future life. To the extent the myelomeningocele itself or other complications (such as respiratory problems, infection, anesthetic risk, or other factors) present, in the exercise of reasonable medical judgement, contraindications to the surgery, the infant is not able to benefit, in spite of his or her handicap, from the surgery. However, if the surgery would be medically beneficial, in that it would be likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding infection or other fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is *because* of the handicap and *in spite of* the infant's being qualified to receive the surgery.

In both the Down's syndrome and myelomeningocele examples, this analytical framework accomplishes precisely what Congress intended in enacting section 504: to overcome stereotypes and prejudices against handicapped persons who are, in spite of their handicaps, able to participate in and benefit from, activities and services supported by Federal funds.

All of this is not to say that application of this analytical framework in every case will be easy. Nonetheless, in spite of the difficulties which may arise in case-by-case applications, the analytical framework focusing on the provision of medically beneficial treatment to handicapped infants is the correct one under the statute, and is capable of application.

Applicability of Section 504 When Hospital Is Incapable of Providing Treatment

A number of commenters questioned the applicability of section 504 in cases where the hospital, due to lack of sophisticated equipment, medical specialists, or other factors, is incapable of providing the treatment needed by a particular infant. These commenters appeared to suggest that the Department would find such a hospital to be in violation of section 504 because it did not provide the medically beneficial treatment it was unable to provide.

Response

The answer on the applicability of the law in such a case is as clear as the applicability of common sense. Common sense indicates that if a patient needs treatment which a hospital cannot provide, the hospital will try to refer the patient to a facility that can provide it. If the patient is handicapped, the common sense response is the same. The failure of the hospital to itself provide the treatment is not "on the basis of the handicap"; rather, nontreatment is based on the fact that the hospital is incapable of providing the treatment.

Similarly, if the medically indicated course of action for any individual with a condition the facility is incapable of treating is to arrange for that individual to be transferred to a facility where the treatment can be provided, then this transfer cannot be denied to a qualified handicapped person (one who will benefit medically from it) on the basis of the person's handicap.

Responsibilities of Hospitals as Opposed to Physicians

Another challenge to the Department's application of section 504 to health care for handicapped infants was submitted by the Federation of American Hospitals:

> . . . A hospital cannot practice medicine. In fact, many state laws prohibit and punish the unauthorized practice of medicine. Nevertheless, the proposed rules place the responsibility for the physician's decision on the hospital. Moreover, assuming that discrimination on the basis of handicap exists, it is *not* discrimination on the part of the hospital, it is the discrimination of the physician and/or parents who are not recipients of federal financial assistance as that term is defined under the Rehabilitation Act. Therefore, insofar as they apply to hospitals, not physicians and parents, the proposed rules are also totally misdirected.

Response

The Department disagrees with the comment's implications that the law in any way requires hospitals to engage in the unauthorized practice of medicine, and that hospitals have no authority to prohibit discrimination by physicians.

It is the Department's view that a hospital has the authority to condition a physician's staff membership or renewal of membership on an agreement to abide by the hospital's policy of nondiscrimination. Indeed, the Department's conditions for hospital participation in the Medicare program require that a hospital have "an effective governing body legally responsible for the conduct of the hospital as an institution." 42 CFR 405.1021. Those conditions also require that a hospital have:

> a medical staff organized under bylaws approved by the governing body, and responsible to the governing body of the hospital for the quality of all medical care provided patients in the hospital and for the ethical and professional practices of its members.

42 CFR 405.1023.

Under those conditions the medical staff is also "responsible for support of . . . hospital policies." 42 CFR 405.1023(a). Standards set forth in the accreditation manual for hospitals, published by the Joint Commission on Accreditation of Hospitals, also recognize the responsibility of the governing body to adopt and approve bylaws consistent with all applicable laws and regulations. The accreditation manual also emphasizes that the governing body has the responsibility for the conduct of the hospital's operation and that the medical staff is responsible to the governing body.

It is the Department's position therefore that a hospital has the right to establish and implement a policy of nondiscrimination among its employees and medical staff, and that this does not constitute an unauthorized practice of medicine by the institution.

Applicability of Section 504 to Adults

Several commenters raised the issue whether section 504 would also be applicable to issues relating to medical care provided to adults. For example, the Department received the following comment from a doctor in San Antonio, Texas:

> As a doctor who practices on adult patients, what I find most worrisome about this whole sorry affair is that the reasoning behind the proposed rules applies at least as well to adults as to infants with congenital defects. Should every patient, no matter how old or ill, be forced to receive the "benefits" of cardiopulmonary resuscitation? Should a ninety-year-old man with a stroke which has caused him to develop pneumonia be subjected to weeks on a respirator in hopes of getting him well enough to go to a nursing home, where the same basic problem is sure to lead to another bout of pneumonia? Should a senile, combative eighty-year-old lady with a breast mass have a biopsy and mastectomy? Certainly a stroke and senility are handicaps if Down's syndrome is.

Response

Although section 504 is, of course, applicable to issues relating to health care provided to adults, the unique issues relating to health care for handicapped infants significantly affect the application of the law and justify the special procedures established by the final rules.

The special needs of infants and minors have long been recognized by most states, as its evidenced by the enactment of child abuse and neglect statutes. These statutes, in most instances, specifically reference the failure to provide necessary medical care to minors as constituting child abuse or neglect, and establish special remedial authorities.

In contrast, most adult patients are viewed by courts as being competent to give or withhold consent regarding medical treatment for themselves. In the case of adults incapable of making decisions, due to senility, mental retardation, or the like, courts have applied the "substituted judgment" doctrine to try to ascertain the incompetent patient's own wishes through available evidence and by asking what a reasonable person in the patient's situation would do.

The circumstances which give rise to the special procedures established by every state to protect children are the same circumstances which give rise to the special procedures established by the final rules to apply section 504 to matters relating to health care for handicapped infants.

Limitations on Obligations Imposed By Section 504

A number of commenters called attention to judicial decisions indicating limitations on the extent to which section 504 mandates that recipients of Federal financial assistance undertake substantial changes in their programs or activities.

As stated by the American Academy of Pediatrics:

> Case law interpreting section 504 suggests the existence of limitations beyond which the statute cannot reach, giving rise to the question of whether HHS' rule would impose on providers unwarranted affirmative action burdens. In *Southeastern Community College v. Davis*, 442 U.S. 397 (1979), the Supreme Court considered the claims of a licensed practical nurse that her denial of admission to a college nursing program on the basis of her hearing disability violated section 504. The college had determined that Davis's impairment was such that, even with a hearing aid, she would be unable to participate fully in the program and function effectively as a nurse. According to the plaintiff, however, the college should not have taken her handicap into account in determining whether she was "otherwise qualified" for the program, but, rather, should have confined its inquiry to her academic and technical qualifications. The Court rejected this argument, finding that section 504 "by its terms does not compel educational institutions to disregard the disabilities of handicapped individuals. . . ." 442 U.S. at 405.
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> Davis argued further that HHS regulations implementing section 504 required that the nursing program be modified to accommodate her, to which the Court replied:
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> If these regulations were to require substantial adjustment in existing programs beyond those necessary to eliminate discrimination against otherwise qualified individuals, they would do more than clarify the meaning of § 504. Instead, they would constitute an unauthorized extension of the obligations imposed by that statute. *Id.* at 410. . . .

Response

The only affirmative step required of recipient hospitals by the final rules is to post an informational notice. As explained in the preamble, the Department has sought to tailor the notice, with respect to both its wording and the locations for its posting, so as to avoid any disruptive or administratively burdensome effects. The posting of notices to advise individuals of protections provided by Federal laws is very common in connection with a wide range of civil rights, health and safety, consumer protection, labor standards, and other Federal laws. The posting of this notice cannot be credibly argued to constitute the kind of excessive regulation prohibited by the *Davis* doctrine.

The other provisions of the final rule which affect hospitals, the clarification regarding access to records and the narrow exception to the ten-day notice rule, similarly impose no appreciable administrative burdens on hospitals. The provision of the final rules relating to state child protective services agencies also, as explained in the preamble, imposes no significant burdens.

The case-by-case application of section 504 and existing regulations, entirely separate from any mandatory provision of the final rules, is, of course subject to the *Davis* limitations. However, as clearly evidenced by the guidelines set forth in the appendix to the final rules, these limitations have been fully complied with in connection with the Department's interpretations of the application of section 504 and in its enforcement processes.

Section 504, as the *Davis* decision recognized, requires the operation of a recipient's program in a nondiscriminatory fashion. The Department's interpretations and procedures applicable in this context require no more. The guidelines in the appendix make clear the Department interprets section 504 as not requiring the provision of futile treatments and as respecting reasonable medical judgments. Further, they make clear that investigative procedures have been specially crafted to avoid substantial administrative burdens. The basis of the Supreme Court's decision in *Davis* was that because the Court found it unlikely that the plaintiff could benefit ultimately from the nursing program, the college's refusal to make substantial modifications to its educational program to accomodate the plaintiff was not discriminatory. The appendix guidelines make clear that the Department's interpretation of section 504 in this context carefully adheres to this ability to benefit requirement.

The *Davis* decision did not authorize the evasion of section 504 obligations under the guise that adhering to the nondiscrimination mandate may require some attention. However the courts ultimately refine the doctrine that there are limitations on the scope of section 504, it is the Department's firm position that those limitations are in no way touched by the mandatory requirements of the final rules, nor will they be touched by case-by-case application of the law consistent with the guidelines set forth in the appendix to the final rules.

Medicare and Medicaid as "Federal Financial Assistance"

A number of commenters also disputed the Department's legal authority for the rules on the grounds that participation by hospitals in the Medicare and Medicaid programs did not bring them within the coverage of section 504 on the grounds that Medicare and Medicaid are not

"Federal financial assistance" within the meaning of the Act.

Response

The Department's position, consistently held since the Medicare and Medicaid programs were originally enacted in 1965, that Medicare Part A payments to hospitals and Medicaid constitute Federal financial assistance for purposes of applicability of Title VI of the Civil Rights Act of 1964 and the nondiscrimination statutes modeled after it, including section 504, is unchanged.

Because the rules do not specifically refer to the Medicare or Medicaid programs, the validity of the rule is not dependent upon the Department's longstanding interpretation. However, hospital officials who believe their hospitals are not subject to these civil rights laws may wish to inform themselves of the Department's position and the substantial legal support for it.

The Department's position has been clear, unequivocal, and consistent. The appendix to the Department's title VI regulations lists Medicare and Medicaid as programs of Federal financial assistance. 45 CFR Part 80, Appendix A, Part 1, No. 121, and Part 2, No. 30. The appendix to HHS's section 504 regulations makes clear HHS's interpretation that the scope of jurisdiction of section 504 is the same as that for title VI. 45 CFR Part 84, Appendix A, Subpart A, No. 2.

The legislative history of the Medicare statute makes clear that Medicare payments to hospitals were intended to constitute Federal financial assistance for purposes of the applicability of title VI of the Civil Rights Act, and thus section 504 as well. Speaking on the floor of the Senate in support of the Medicare bill, Senators Ribicoff and Hart stated unequivocally that title VI was applicable to hospitals participating in Medicare. Senator Ribicoff: "[H]ospitals and other institutions have . . . to abide by Title VI of the Civil Rights Act." 111 Cong. Rec. 15803 (1965). Senator Hart:

> In addition to the new economic independence it will create, I am hopeful that the bill will promote first class citizenship in another fashion also. We decided last year, and wrote into law, that federal tax dollars collected from all the people may not be used to provide benefits to institutions or agencies which discriminate on the grounds of race, color, or national origin. This principle will, of course, apply to hospital and extended care and home health services provided under the social security systems, and *will require institutions and agencies furnishing these services to abide by Title VI of the Civil Rights Act of 1964*. Id. at 15813 [emphasis supplied].

In addition, the legislative history of the Civil Rights Act supports this position. In the most complete analysis of title VI contained in the House Judiciary Committee's Report, the additional views of seven supporters of the legislation, uncontroverted in any section of the report, specifically made reference to the predecessor program to Medicaid and clearly stated congressional policy underlying title VI:

> In a related fashion, racial discrimination has been found to exist in vendor payment programs for medical care of public assistance recipients. Hospitals, nursing homes, and clinics in all parts of the country participate in these programs and, in some, Negro recipients have received less than equal advantage.
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> * * * * *
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> In every essential of life, American citizens are affected by programs of Federal financial assistance. Through these programs, medical care, food, employment, education, and welfare are supplied to those in need. For the government, then, to permit the extension of such assistance to be carried on in a racially discriminatory manner is to violate the precepts of democracy and undermine the foundations of government.

H.R. Rep. No. 914, 88th Cong. 2d Sess. (Additional Views on H.R. 7152 of Hon. William M. McCulloch, et al.).

Courts which have dealt with this issue have found Medicare and Medicaid to constitute Federal financial assistance for purposes of establishing civil rights jurisdiction. A recent such case is *United States* v. *Baylor University Medical Center*, 564 F. Supp. 1495 (N.D. Tex. 1983). Citing HHS regulations indicating that Medicare and Medicaid are Federal financial assistance, case law in which courts "have had little difficulty" in finding that they are Federal financial assistance, the legislative history of the Medicare statute, long-standing agency interpretation, and the broad construction which must be given to remedial civil rights statutes, the court found that Medicare and Medicaid are Federal financial assistance for purposes of section 504 coverage. The court also specifically rejected the medical center's argument that Medicare and Medicaid payments are exempt from the definition of "Federal financial assistance" on the grounds of being under contracts of insurance. The Court distinguished insurance programs, by noting that Medicare is funded by mandatory taxes and Medicaid by general revenues, rather than through a system of risk-based premiums.

Other cases supporting the position that Medicare and Medicaid payments are Federal financial assistance are *NAACP* v. *Wilmington Medical Center*, 657 F.2d 1332 (3d Cir. 1981) (the court noted its jurisdiction was based on the hospital's receipt of Medicare and Medicaid funding); *United States* v. *Cabrini Medical Center*, 497 F. Supp. 95, 96, n.1 (S.D.N.Y. 1980); *Cook* v. *Oschner*, No. 70–1969 (E.D. La., Feb. 12, 1979) (the defendants' argument that Medicare and Medicaid payments did not constitute Federal financial assistance was rejected by the district court during pre-trial motions); *Flora* v. *Moore*, 461 F. Supp. 1104, 1115 (N.D. Miss 1978); and *Bob Jones University* v. *Johnson*, 396 F. Supp. 597 (D.S.C. 1974), *aff'd.*, 529 F.2d 514 (4th Cir. 1975) (court held that VA benefits to students constituted Federal financial assistance to the university and noted their similarity to Medicaid).

The basic congressional policy underlying title VI, section 504 and related statutes is that federally funded programs and services are to be administered in a nondiscriminatory fashion. The Medicare and Medicaid programs were established for the purpose of providing medical service to people who otherwise might not be financially able to obtain them. The argument that somehow these federally assisted medical services were not intended to be within the reach of the nondiscrimination rule is clearly contrary to the basic congressional policy. Underscoring this is the fact that HHS spends billions of dollars annually for health care services to the aged, disabled, and poor, and virtually all hospitals participate in these programs. According to data of the Health Care Financing Administration (HCFA), HHS, of approximately 6,930 hospitals, 6,737 participate in Medicare and virtually the same number in Medicaid. In fiscal year 1982, total hospital costs in the United States were $136 billion. Of this, $47.9 billion were HCFA expenditures ($36.3 billion, Medicare, $11.6 billion, Medicaid). Approximately 36 percent of all hospital costs in the United States are financed through the Medicare and Medicaid programs. *See HCFA Statistics* (Publication No. 03155, Sept. 1983).

It should also be noted that there are no persuasive arguments for distinguishing Medicaid and Medicare on the question of whether they constitute Federal financial assistance to hospitals. Although Federal Medicaid funds flow through the states, the states' relationship to the hospitals in Medicaid is essentially the same as that of the Federal government to the hospitals in Medicare. HHS regulations for both title VI and section 504 specify that recipients of Federal financial assistance include all subrecipients which receive funds from a recipient. 45 CFR 80.13(i), 84.3(f).

In addition, Medicare and Medicaid cannot be considered procurement contracts for purposes of the statutory exemption from civil rights jurisdiction in connection with such contracts. Unlike the relationship that exists under procurement contracts, health care providers promise only that if they serve an eligible beneficiary of the program, they will look to the government for payment of all but specified items. In addition, under Medicare and Medicaid the level of services is determined by providers who are not acting as agents for the government and are not discharging an obligation the government has assumed. Rather they are—with Federal assistance—engaging in activities they have long performed. In this respect Medicare and Medicaid payments are indistinguishable from grants to pay the costs of medical services. Indeed, those payments often cover medical costs of indigent patients that hospitals would otherwise be required to absorb pursuant to their other legal obligations. In contrast, under a procurement contract the government acts on its own account as a consumer of goods, such as typewriters and paper clips, or services, such as hotel accommodations and rental car services for traveling employees. The level of services under procurement contracts is determined by the government and not, as under Medicaid or Medicare, by the provider.

Furthermore, the Medicare and Medicaid programs do not fall within the statutory exemption from the definition of Federal financial assistance for any payments pursuant to "a contract of insurance or guaranty." 42 U.S.C. 2000 d-1, 2000 d-4 (title VI); 45 CFR 84.3(h) (section 504). The principal object of the Medicare and Medicaid programs is to provide service. Medicare and Medicaid programs cannot properly be characterized as, or analogized to, a contract of insurance. Benefits under these programs are not measured by any fixed premium paid by the beneficiary to the government; the government reimburses for the reasonable cost incurred by the provider in rendering services. Missing from both reimbursement plans is that essential element of insurance—the assumption of risk. The Medicare and Medicaid programs do not purport to indemnify for nonpayment by the beneficiary. The hospital, in becoming a provider of services under these programs, agrees to look to the government for payment and to accept the reimbursement from the government as full payment, except for the deductible and coinsurance. The beneficiary does not incur any obligation to pay for those services which are covered by the agreement between the provider and the government.

Nor do Medicare and Medicaid constitute contracts of guaranty. Essential to a definition of a contract of guaranty is a primary obligation on the part of the individual for whom the guaranty is given. A contract of guaranty is a promise to pay or an assumption of performance of some duty upon the failure of another who is primarily obligated in the first instance. In contrast, the reimbursement provisions of the Medicare and Medicaid programs are not activated by the failure of the individual recipient to pay for the medical services covered by agreement between the government and the hospital.

It is the absence of these elements which distinguishes Medicare and Medicaid from programs that Congress intended to be excluded under the contract of insurance or guaranty exception, such as mortgage guarantees under FHA or VA and depositors' insurance under FDIC, where the role of the government is clearly as an insurer or guarantor and Federal monies are involved only if the private party does not meet his or her obligation. It is also noteworthy that the American Hospital Association apparently concluded in 1966, when Medicare was instituted, that hospitals receiving Medicare were recipients of Federal financial assistance for title VI purposes. The AHA solicited and printed in its journal a question and answer article prepared by the former Department of Health, Education and Welfare to help hospitals understand what they were required to do to comply with title VI to receive Medicare funds. *See* "Hospitals and Title VI of the Civil Rights Act of 1964, Questions and Answers," *Hospitals*, June 1, 1966. Also, pursuant to 45 CFR 84.5, hospitals which participate in the Medicare and Medicaid programs have submitted assurances to HHS that they would comply with section 504 and the applicable regulations.

Accordingly, as demonstrated by this brief summary of points in support of the Department's long-standing position, hospitals which participate in the Medicare and Medicaid programs are recipients of Federal financial assistance for the purpose of establishing section 504 jurisdiction.

"Program or Activity" Receiving Federal Financial Assistance

Another argument presented by some commenters to dispute the legal authority for the proposed rule is that even if Medicare and Medicaid are "Federal financial assistance," they are not "a program or activity" which provides medical care to handicapped infants. The argument appears to be that, purportedly following the analysis of the government's brief to the Supreme Court in the pending case of *Grove City College* v. *Bell*, 687 F.2d 684 (3d Cir. 1982), *cert. granted*, 51 USLW 3611, February 22, 1983 (#82-792), the "program or activity" which receives Federal financial assistance in the form of Medicare and Medicaid payments to a hospital is the fiscal accounting office of the hospital.

As stated by the American Academy of Pediatrics:

> . . . to the extent, then, that the government believes that Title IX cannot extend beyond the financial aid office, is difficult to understand how section 504 could extend to nurseries, maternity wards, and neonatal intensive care units simply because the medical expenses of primarily elderly Medicare beneficiaries are reimbursed in the accounting office.

Response

The Department believes this argument is without merit. The position advanced by the government in *Grove City* is that in determining what constitutes the Federally assisted program, it is necessary to examine both the nature of the Federal program and the organizational practices of the recipient institutions. *Grove City* involves the Basic Education Opportunity Grants program (BEOG), in which grants are made to students and used by the students to pay for tuition, fees, room and board. The recipient institutions operate financial aid programs under the direction of a financial aid office, with a separate budget and a specific purpose, to provide financial aid to students who otherwise could not afford to attend the college. BEOG's are one component of the college's financial aid program. In view of the nature of the Federal BEOG program and the organizational practices of colleges, it is the college's financial aid program that receives the Federal assistance. Although, conceivably, an effort could be undertaken to "trace" the "ripple effects" of the BEOG money throughout the college, the government's position in *Grove City* is that this is not what Congress intended in enacting the program specificity requirement in the applicable civil right statutes.

The circumstances involved in connection with Medicare and Medicaid reimbursements to hospitals are entirely different from those involved in BEOG's and colleges. Rather than providing assistance to a general financial aid program operated by the recipient. Medicare and Medicaid payments to hospitals are primarily for particular medical services provided to particular patients who received services in particular units of the hospital. It is services provided to particular beneficiaries by the hospital's operating room, x-ray department, laboratory, pediatrics ward, or other organizational units that give rise to the Federal reimbursements. In addition, the hospital's organizational and accounting practices provide for Federal reimbursement for a proportionate share of administrative costs, housekeeping, depreciation of physical plant, and other general expenses, all specifically itemized and specifically eligible for reimbursement.

Also unlike colleges, "tracing" Medicare and Medicaid reimbursements within hospitals is not dependent upon looking for "ripple effects" of the Federal funds. Rather, it is the specific identification of actual services and costs which gives rise to reimbursements based specifically thereon.

Therefore, the Federally assisted program of a hospital is not, as a commenter suggested, the accounting office of the hospital, any more than the Federally assisted program of a college is the accounting office or comptroller. An examination of the applicable Federal programs and the recipient's organizational practices makes clear that the issues presented in the *Grove City* case, and the positions taken by the government in that case, do not undermine the legal basis for the final rules or the application of section 504 to health care for handicapped infants.

It should also be noted that whatever subtleties or twists are ultimately associated with the interpretation of "program or activity," the final rules specifically accommodate the program specificity requirement pertaining to the posting of the informational notice as applicable to each recipient that provides health care services to infants "in programs or activities receiving Federal financial assistance." If, on the basis of the Supreme Court's eventual decision in *Grove City* or other factors, limitations evolve on what programs or activities of hospitals are covered by section 504, those limitations will be accommodated by the text of the rules.

Services vs. Employment as Jurisdictional Limitation

The Federation of American Hospitals advanced another argument in behalf of the proposition that the Department has no legal authority to issue the final rules. The Federation commented:

> The Rehabilitation Act of 1973 (Pub. L. 93-112) does *not* apply to hospitals. Federal circuit courts of appeal which squarely address the issue uniformly hold that the Act does *not* apply to hospitals as recipients of Medicaid or Medicare funds. These courts have held that the Rehabilitation Act applies to recipients of federal financial assistance if, and only if, that assistance has the primary objective of providing employment.
>
> In *United States* v. *Cabrini*, 639 F.2d 908 (2d Cir. 1981), the Court . . . [held] that the Office for Civil Rights was not authorized to investigate a complaint by a hospital employee that he was discharged for mental disability. . . . *Trageser v. Libbie Rehabilitation Center, Inc.*, 590 F.2d 87, 89 (4th Cir. 1978), *cert. den'd*, 442 U.S. 947; *Scanlon v. Atascadero State Hospital*, 677 F.2d 1271, 1272 (9th Cir. 1981); see, also, *Carmi v. Metropolitan St. Louis Sewer District*, 620 F.2d 672, 674–675 (8th Cir. 1980), *cert. den'd*, 101 S. Ct. 249 (1980) . . .
>
> As there is no legal authority supporting the proposition that the Rehabilitation Act of 1973 applies to hospitals receiving Medicare and Medicaid funds since the primary objective of those programs is *not* employment; the proposed rules must be withdrawn.

Response

The Federation's legal argument is incorrect. The *Tragesar/Carmi/Cabrini Scanlon* line of cases holds that section 504 does not provide jurisdiction *over employment practices of recipients* unless the Federal financial assistance has the primary objective of providing employment. These cases held that section 505(a)(2) of the Rehabilitation Act, making the "remedies, procedures, and rights set forth in title VI of the Civil Rights Act of 1964" applicable to section 504, incorporated the restriction in section 604 of the Civil Rights Act of 1964, which makes title VI inapplicable to employment practices unless the Federal financial assistance has the primary objective of providing employment. Two circuit courts have recently held that the reference to title VI procedures in section 505 did not intend to incorporate the employment restriction. *Jones* v. *Metropolitan Atlanta Rapid Transit Authority*, 681 F.2d 1376 (11th Cir. 1982), *petition for cert. pending*, No. 82-1159 (filed January 11, 1983); *LeStrange* v. *Consolidated Rail Corporation*, 687 F.2d 767 (3d Cir. 1982), *cert. granted*. The Supreme Court is expected to decide this issue during its present term.

Regardless of the merits of that issue, it has no relevance to the final rules. No case has held, as none could based on the clear statutory language and congressional intent of section 504, that section 504 applies only to a very narrow segment of employment practices, and has no applicability to the provision of services and benefits under programs and activities receiving Federal financial assistance.

B. ENFORCEMENT PROCESSES

A prior section of this preamble discusses investigative procedures of the Department applicable in the context of health care for handicapped infants and an analysis of related comments. This section discusses other comments pertinent to this issue.

Sanction for Non-Compliance

A number of commenters stated objections to the sanction for non-compliance, termination of Federal financial assistance. The basic thrust of these comments was that termination of all or a portion of a hospital's Federal financial assistance would be unfair in the context of difficult treatment decisions, later judged by HHS to be in non-compliance with section 504. As stated by the American Hospital Association:

> The penalty for even inadvertent violation would be severe. The Department asserts authority and threatens to terminate all federal financial assistance that the individual or institution may be receiving. Moreover, the threat of such penalties may encourage physicians and others to refuse to participate in programs funded by the Federal government, particularly those supporting specialized treatment facilities for the newborn. In cases where the institution depends for operation on significant federal funds unrelated to handicaps, this policy may, for example, cause the closing of neonatal units to avoid the risk of losing federal funds. Such a result could reduce access to needed care for many infants who could be helped with safe, timely and effective treatment.

Response

It is correct that under the law, non-compliance with section 504 can result in termination of Federal financial assistance to the particular program or activity, or part thereof, in which the noncompliance has been found. However, the existing procedural and legal requirements applicable to any action to terminate Federal financial assistance are more than adequate to protect against an unfair result.

The Rehabilitation Act provides, in section 505(a)(2), that the remedies, procedures and rights set forth in title VI of the Civil Rights Act of 1964 shall be applicable to actions to enforce section 504. These title VI procedures provide substantial due process protections.

First, before Federal financial assistance can be terminated, the recipient must have an opportunity for a hearing before a court or administrative law judge, who must expressly find that there has been a failure to comply with the law or applicable regulations.

Second, before Federal financial assistance can be terminated, their must be a finding that compliance cannot be secured by voluntary means. Therefore, a recipient that has been found to have violated section 504 in connection with the health care provided to a handicapped infant will not lose its Federal funding unless it refuses to adopt the standards or procedures necessary to prevent future noncompliance.

Third, in any case, the burden of proof that there has been noncompliance and that it cannot be corrected by voluntary means is on the government. The standards for this determination are those set forth in the appendix to the final rules which includes the guideline regarding deference to reasonable medical judgments.

Fourth, the Department's regulations provide for appeal of adverse administrative law judge decisions to the Department's Civil Rights Reviewing Authority, which is independent from the Office for Civil Rights. Recipients may then seek review by the Secretary of the decisions of the Reviewing Authority. Further, the Department's final decision is subject to judicial review.

Therefore, there is no basis for an assertion that Federal financial assistance can be precipitously terminated on the basis of some subjective determinations by a handful of bureaucrats. In fact, due primarily to the statutory requirement that recipients be given full opportunity to voluntarily comply, the chance, based on all prior governmental experience under title VI and the statutes modeled after it, that any recipient will actually lose its Federal financial assistance is rather remote.

OCR Investigations at Strong Memorial Hospital and Vanderbilt University Hospital

In support of criticisms of OCR investigations, a number of commenters cited reports of hospitals which were subjects of OCR investigations at the time the interim final rule was put into effect in March. As stated by the American Hospital Association:

> The mischief of the federal hotline enforcement mechanism was illustrated graphically during the short life of the March rule by the occurrances at Vanderbilt University Hospital in Nashville and Strong Memorial Hospital in Rochester, NY. In the Vanderbilt case, an anonymous hotline caller alleged that ten named children at the hospital were not being fed or given proper medical care. A federal "Baby Doe squad" (consisting of lay officials from the regional and national staffs of the Office of Civil Rights and a hired neonatologist) arrived at the hospital that evening and met with the attending physicians for each of the children, the chief of pediatrics, the chief pediatric resident, and the associate director for nursing, after which the neonatologist examined each child. On the following day, the investigative team examined medical records and interviewed nursing staff, hospital administrators, and the chief of pediatrics.
>
> [The investigation] resulted in the delayed discharge of one patient, delayed the transporting of children to scheduled surgery, necessitated the re-ordering of laboratory reports, diverted nurses from patient assignments, delayed nursing shift reports, and consumed, in total, substantial amounts of professional time that otherwise would have been devoted to the care of patients, including the infants who were the subjects of the investigation.
>
> The Strong Memorial experience was strikingly similar and even more disturbing. An unidentified hotline caller, whose only information concerning the case apparently came from a newspaper report, triggered an investigation regarding the treatment of conjoined twins in that facility. An identically constituted investigative squad arrived at the hospital, though without any statement of investigative authority or written requests for hospital records. The hospital complied nonetheless with the investigators' requests, only to have the team disagree as to which of them was entitled to the information. The neonatologist member of the team subsequently departed upon learning that the investigators had failed to obtain the parents' consent to examine the infants.
>
> The effects of the investigation in this case went well beyond the diversion of patient care resources and delays in treatment. The parents of the conjoined infants were subjected to substantial undesired publicity. Parents of other critically-ill children were led by this publicity and the lack of clarification from federal investigators to become apprehensive about the adequacy of care provided at Strong Memorial. Before the investigation concluded, one family removed its seriously-ill child from the facility prior to the completion of treatment, on the belief that the hospital was intentionally harming children.

Response

The Department strongly disputes the accounts of these investigations provided by personnel affiliated with the two hospitals. The reports referenced by commenters appear to be based upon affidavits prepared in connection with litigation initiated by the American Hospital Association challenging the implementation of the March interim final rule. Contrary to these reports, both of these investigations were conducted very expeditiously and professionally, and every effort was made to minimize any disruption to the hospitals. In addition, during the course of these investigations (and prior to their being raised in the litigation), officials of neither hospital complained to OCR regarding the conduct of the investigations, nor, in either case, did hospital personnel complain to OCR personnel that the investigations were causing significant disruptions to the patient care activities of the hospital.

With respect to the Strong Memorial Hospital case, the following are the pertinent facts of the investigation:

a. On the morning of March 29, 1983 (seven days after the effective date of the interim final rule), a complaint was received on the hotline about conjoined infants recently born at Strong Memorial Hospital in Rochester, New York.

b. An investigative team consisting of one investigator from the Washington Office and two from the New York Regional Office was sent to the site to investigate. The team arrived at approximately 4:30 p.m. Arrangements were made to have a medical consultant also travel to the site.

c. The team met with a hospital administrative officer and the attending physician. The attending physician reviewed the infants' condition and status. He mentioned that there was a no-resuscitation order in effect for the twins, should cardiac arrest occur.

d. The attending physician told OCR that the parents were concerned about publicity. OCR assured him that OCR would not discuss the case with the media or otherwise publicize OCR's investigation.

e. The OCR team made no request to interview other staff at that time. The administrator produced a copy of the medical records. The Washington Office investigator received it and said it would not be necessary to produce another copy for the Regional Office. Throughout the investigation, the administrator and attending physician were cooperative and helpful. The attending physician asked the team leader to tell the OCR medical consultant that he could be called late and would be glad to come to the hospital and meet with him, show him the medical records, and let him view the infant. The administrator asked to be called when the medical consultant arrived. The OCR team left the hospital at about 7:30 p.m.

f. The OCR medical consultant arrived in Rochester about 9:15 p.m. and met with the investigative team. Apparently based on a misimpression of his role, the consultant stated he would not review the records or go to the hospital to meet with the physician or view the infants unless the parents consented.

g. On the morning of March 30, 1983, the OCR team and the OCR medical consultant had a telephone conversation with the administrator. He said that he wished the OCR team would not return to the hospital because that investigation was receiving publicity. The team leader decided there was no need to return to the hospital.

h. In summary, the investigative team was on site only three hours in the late afternoon and early evening of March 29.

With respect to Vanderbilt University Hospital, following are the pertinent facts of the case:

a. OCR received a hotline telephone call at 11:45 a.m. on March 23, 1983 (the day after the effective date of the interim final rule), alleging that ten infants at Vanderbilt University Hospital were not receiving treatment and/or nourishment.

b. From 9:30 p.m. to 11:45 p.m. on March 23, 1983, the OCR investigative team, consisting of two investigators from the Atlanta Regional Office, one from the Washington Office, and the OCR medical consultant, met with various members of the hospital staff to discuss the current status of the ten infants.

c. After this meeting, from midnight until 12:30 a.m., the OCR medical consultant physically viewed the infants on the regularly scheduled "rounds" in the company of the Chief Pediatric Resident and the Chief of Pediatrics.

d. From 8:00 a.m. until 2:45 p.m. on March 24, 1983, the OCR investigators and medical consultant reviewed the available medical records of the ten children. Medical records were given to OCR in groups of four and retrieved as needed by the Associate Director of Nursing and other members of the Vanderbilt staff. The Associate Director of Nursing and the hospital staff members were very cooperative, and at no time did they indicate to the investigative team that the review of records was causing any problem. In only one instance did they indicate they needed a chart, and OCR immediately relinquished it. That chart was not subsequently made available for review that day, but a copy of it was mailed to OCR.

e. All records were reviewed with the understanding that if they were needed for patient care they would be retrieved. Computer printouts detailing the admitting diagnosis, age, physician assigned to the case, service area, and the date of admission or transfer for all ten children were given to the OCR team. The Associate Director of Nursing stated that this printout was readily available because the information was kept on-line for billing purposes and this would not interfere with patient care. The bedside charts were copied and given to OCR at the end of day because they were needed for patient care.

f. Following the OCR review of the medical records, from approximately 2:45 p.m. to 4:00 p.m. on March 24, 1983, the OCR team interviewed the available nurses who were involved in the primary care of the infants. Five nurses were interviewed for approximately 10 to 15 minutes each. The selection of the nurses was left to the discretion of the Associate Director of Nursing; she scheduled them so that patient care would not be disrupted.

g. At no time did the Chief of Pediatrics or Associate Director of Nursing indicate that the OCR investigation was placing patients in jeopardy.

h. The hospital staff asked the OCR team for a preliminary statement of findings. The team leader responded that OCR investigators are not authorized to make findings during an investigation. An investigative report would have to be prepared following the investigation, and this would have to be reviewed before the agency could issue findings.

i. The total time spent on-site to investigate the circumstances relating to all ten infants was approximately eleven hours. The total time occupied of the two Vanderbilt doctors directly involved was seven and one-half hours. Every effort was made to minimize any disruption, and at no time during the investigation did hospital personnel complain to OCR that the investigation was disrupting patient care.

Therefore, contrary to the reports of hospital officials, prepared to support litigation against the Department, these investigations were conducted professionally and every effort was make to minimize any disruptions.

Concerning the report that, according to a hospital official, one family withdrew a seriously ill patient from the Strong Memorial Hospital before completion of treatment due to fears that the hospital was intentionally harming children, caused by their reading of local newspaper accounts of the investigation, the report provided no further details, and the department has no basis to confirm the event or the motivations for it. However, the firm policy of not commenting to the media regarding an open investigation was adhered to strictly in the Strong Memorial Hospital case. Media attention was not provoked by OCR, nor did OCR make any statement to the media which could have implied any belief by OCR that the allegations of the complaint were substantiated.

Danger of Overtreatment

Several Commenters expressed the concern that the existence of OCR's enforcement process would cause hospitals and health care professionals to "overtreat" an infant. An example of this is a case in which the attending physician or physicians have concluded on the basis of reasonable medical judgment that treatment would be futile, but, due to a fear that an OCR investigation might come to a contrary conclusion, nevertheless provide futile treatment, which, while prolonging the process of dying, causes suffering to the infant and severe distress to the infant's parents. In connection with adverse ramifications of overtreatment, attention was called to the experiences of one family, as presented in a recent book, *The Long Dying of Baby Andrew* (Little, Brown and Co., Boston, 1983).

Response

The Department believes that whatever the dangers are that physician misjudgments will lead to "overtreatment" of infants, those dangers are not increased by the existence of section 504 or the determination of the Department to see that it is effectively enforced. As indicated above, section 504 does not require that futile treatments, which will do no more than prolong the act of dying, be provided. Moreover, OCR decisions concerning compliance or noncompliance with section 504, informed by the expert evaluation of qualified medical consultants, do not interfere with reasonable medical judgments. Also, in any case, reviewing whether certain care was medically indicated and denied on the basis of the infant's handicap, there are extensive due process protections to assure accuracy of fact finding. Furthermore, even where there is an ultimate finding, after exhaustion of all due process rights, of noncompliance of section 504, no sanction can be implemented unless the recipient hospital refuses to adopt procedures to bring it into compliance.

The Department agrees that in a "close case" it may be prudent to preserve the status quo pending additional consideration regarding whether certain possible treatments are medically indicated, whether that additional consideration is by specialists at the hospital, by medical professionals at a more specialized facility, by some internal hospital review board, or by some state or federal agency. In such a case, the usual practice in most hospitals likely would be to continue life-sustaining care until the appropriate analysis has been secured.

C. ALTERNATIVE APPROACHES

In addition to proposals discussed in the preamble concerning establishment of Infant Care Review Committees, the Department received other suggested alternative approaches.

AMA Proposal: Further Study Prior to Action

The American Medical Association proposed that, rather than adopting any regulation, the Department should initiate a study to include: compilation of data on the incidences of each type of severe impairment in newborns and of successful treatment, unsuccessful treatment and nontreatment in each category; identification of the issues involved in medical management and of mechanisms currently used by hospitals and states; determination of the availability of facilities, financial resources, and public and private social services; and an assessment of the impact of the various alternative means of responding to situations involving severely impaired newborns, including such factors as the ongoing treatment of newborns, the families of severely impaired newborns, the operation of health care facilities, the confidentiality of patient-physician relationship, the malpractice and disciplinary risks of health care providers, the availability of facilities and resources, and the costs of care.

Response

The AMA's proposal for an elaborate study prior to taking any action concerning this matter is not acceptable to the Department. The Department does not believe it is necessary—or in some respects, even possible—to generate definitive data, information or conclusions on many of the issues identified in the AMA's study proposal.

Much of the data the AMA proposes be compiled concerning the incidence rates of every classification and degree of serious impairment, of respective modes of treatment, of rates of success, nonsuccess and nontreatment, and of issues, mechanisms, resources and costs is probably impossible to compile. These matters are the subject of an entire discipline of medical practice and study. To suggest that a government study will somehow generate conclusive information on these issues appears naive at best.

The call for a study of the resources available and the costs of care for newborns appears aimed at identifying an aggregate cost to society of putting into practice the principle of providing all handicapped infants with medically beneficial treatment. Because there are no reliable data available on the extent to which handicapped infants are now denied medically beneficial treatment, it would apear impossible to develop even reasonable guesses regarding aggregate costs. Of course, in the overall context of all health care expenditures in the United States, the costs are certain to be relatively small.

In question 6 included in the preamble to the July 5 proposed rule the Department sought input on this cost issue by asking for "examples of cases where medically indicated treatment would, but for the legal requirements of section 504, be withheld." No information was submitted to the Department in response to this question which provides a basis for meaningful cost projections. Although the AMA did not address the issue, other major medical organizations who commented on the cost issue indicated that cost should not be a determinative factor in deciding upon treatment for seriously impaired newborns.

The Department agrees there is utility in assessing the impact of various alternative means of addressing and responding to situations involving severely impaired newborns. Much of this preamble focuses on precisely this issue. Although the AMA did not identify the "various alternative means it believes to exist to deal with this issue, based on the comments received by the Department, there would appear to be three major approaches: (1) Enforcement of section 504 (hereinafter "the section 504 approach"); (2) review by hospital review boards, such as Infant Care Review Committees (hereinafter "ICRC approach"); and (3) the traditional doctor-parent approach.

Concerning impact on treatment of newborns, the section 504 approach is most directly focused on the provision of medically beneficial treatment. The ICRC approach would be organized to have this as its objective, but lacks a mechanism to assure this as a relatively uniform result among thousands of hospitals. The connection between actual practice and this objective appears most potentially attenuated under the traditional doctor-parent approach, under which there are many thousands of individual decisionmaking units.

With respect to the impact on families, to the extent some parents would not consent to medically beneficial treatment, the traditional doctor-parent approach would appear least likely, given the lack of a mechanism to facilitate uniformity, to resort to the system provided by State law to review the propriety of parental decisions. The ICRC approach appears more likely, and the section 504 approach most likely, to produce this result in that they incorporate standards that the lack of parental consent for medically beneficial treatment must be brought to the attention of the appropriate state agencies.

Concerning the impact on the operation of health care facilities, the traditional doctor-parent approach would appear to have the least impact because the facilities have no formalized involvement in the decisionmaking process. Both the section 504 approach and the ICRC aproach would likely result in greater involvement of the health care facility.

With respect to the confidentiality of patient-physician relationships, the traditional physician-parent approach is most protective of confidentiality in that it does not provide for the sharing of information with others. Both the section 504 approach and ICRC approach involve the sharing of information with others, but both incorporate adequate confidentiality safeguards.

With respect to the impact on malpractice and disciplinary risks (assuming that by disciplinary risks, the AMA is referring to revocation of medical licenses, or the like) of health care providers, to the extent physicians have malpractice or disciplinary vulnerabilites relating to incorrect diagnoses or inadequate knowledge of prevailing medical judgments regarding indicated treatments, approaches which facilitate the avoidance of failure to provide medically indicated treatment would appear to reduce those vulnerabilities. Because none of the approaches involve doctors or hospitals overruling parental decisions, and because reports to State agencies of suspected instances of neglect of children are immunized by state law from legal vulnerability, none appear to increase malpractice or disciplinary risks in the context of actions which would be taken when parents refuse consent for medically beneficial treatment.

With respect to the impact on costs, available resources, and available facilities, to the extent the different approaches affect the likelihood that handicapped infants will receive medically indicated treatment, these factors will be correspondingly affected

However, the Department is unaware of any data base for quantifying these factors.

In summary, the Department believes adequate information is on the record to provide a basis for prudent and informed decisions on this issue. Regarding several of the issues raised by the AMA proposal, the Department agrees there would be advantages in having more detailed information and data. However, obtaining more definitive information on some of these issues is impracticable or impossible due to the lack of a reliable data base and a viable methodology to obtain better data. Therefore, the Department believes there would be very little to be gained from another government study of this issue.

D. FACTUAL BASIS FOR FINAL RULES

NPRM Explanation

A number of commenters challenged the Department's factual basis for the proposed rule, as set forth in the July 5 notice of proposed rulemaking. The points argued in support of the position that the factual basis did not provide a sufficient foundation for the regulation were:

(a) Judge Gesell questioned the factual basis for the March 7 rule.

(b) The 1973 article by Drs. Duff and Campbell of the Yale New-Haven Hospital documenting that of 299 consecutive deaths occurring in that special care nursery, 45 (14%) were related to withholding treatment, cited in the preamble to the proposed rule, was too old to be reliable.

(c) The several specific cases cited in the preamble had various probativity defects.

(d) The 1977 article reporting the results of a survey of pediatricians suggesting discriminatory attitudes was outdated, not statistically valid, and otherwise lacked current probative value.

(e) The findings of the report of the President's Commission for Study of Ethical Problems in Medicine and Biomedical and Behavioral Research entitled *Deciding to Forego Life-Sustaining Treatment* contradict the Department's factual basis.

(f) Because "discrimination against the handicapped in the delivery of health care services does not only involve handicapped newborns," there is "no compelling rationale for a set of rules targeted solely at this population."

Response

The Department continues to believe that a substantial factual basis exists for the proposed rule. First, it should be noted that Judge Gesell, although he found many relevant factors to have been inadequately considered in connection with issuance of the March 7 rule, did not find the factual basis inadequate to support "undertaking a regulatory approach to the problem of how newborns should be treated in government-financed hospitals."

Second, the arguments that the well-documented Duff and Campbell study is outdated are based on the personal opinions of several commenters. These personal opinions, although in some cases those of highly-respected medical professionals, were not backed up by any empirical data even remotely resembling the very detailed evidence of the Duff and Campbell study.

Third, the conclusion of the President's Commission that decision-making about seriously ill newborns "usually adheres" to proper standards cannot be fairly represented as evidence that handicapped newborns should be exempt from basic protections of the law prohibiting discrimination on the basis of the handicap.

Fourth, regardless of the caveats concerning the age of particular cases or the lack of a conclusive finding of illegal discrimination, the several specific cases cited in the preamble to the proposed rule support the proposition that handicapped infants may be subjected to unlawful discrimination.

Fifth, in the absence of any empirical studies or data to bolster their personal opinions, the commenters who suggested that the results, published in 1977, of the survey of pediatricians' attitudes are outdated are not convincing. The article, "Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons," 60 *Pediatrics* 588, reported the results of a survey of 400 members of the Surgical Section of the American Academy of Pediatrics and an additional 308 chairpersons of teaching departments of pediatrics and chiefs of divisions of neonatology and genetics in departments of pediatrics. Responses were received from 267 of the former group (66.8%) and 190 of the latter (61.7%). Responses were anonymous. Among the results of the survey were:

—76.6% of the pediatric surgeons and 49.5% of the pediatricians said they would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia if the infant also had Down's syndrome."

—23.6% of pediatric surgeons and 13.2% of pediatricians would *encourage* parents to refuse consent for treatment of a newborn with intestinal atresia and Down's syndrome. Only 3.4% of pediatric surgeons and 15.8% of pediatricians would get a court order directing surgery if the parents refused.

—63.3% of the pediatric surgeons and 42.8% of the pediatricians said in cases of infants with duodenal atresia and Down's syndrome, where they "accept parental withholding of lifesaving surgery," they would also "stop all supportive treatment including intravenous fluids and nasal gastric suction."

—62% of all respondents who believe that children with Down's syndrome "are capable of being useful and bringing love and happiness into the home" would nevertheless acquiesce in parents' decisions not to allow surgery for the atresia. Only 7% who so believe indicate that they would go to court to require surgery.

Sixth, there is no requirement in law or policy for the government to prove the magnitude of illegality before establishing basic mechanisms to allow for effective enforcement of a clearly applicable statute.

Evidence of Problems Submitted by Commenters

Additional evidence of the risk that handicapped infants may be subjected to discrimination was submitted by commenters. For example, the Spina Bifida Association of America stated:

> Unfortunately, the SBAA has direct experience of cases in which this principle [of nondiscrimination] has not been followed—instances in which children with spina bifida have been initially denied appropriate treatment. Pediatric neurosurgeon Dr. David McClone of Chicago Children's Memorial Hospital, a member of SBAA's Professional Advisory Committee, has found that 5% of the children with spina bifida referred to him have been victims of treatment denial. Most of these cases, he believes, resulted from ignorance of current therapies and their impressive outcomes.

The Department received a number of comments from practicing nurses regarding the problem and need for the proposed rule. For example, from a Lexington, Kentucky, nurse:

> I am a registered nurse and have worked in the labor and delivery area, newborn nursery and intensive care nursery. . . . I think the average American would be shocked at the decisions that are made regarding "non-perfect" infants. I have personally heard physicians and nurses talk to new parents about their child and persuade the parents to "let the child die and therefore end its suffering"—which really meant "let us starve your child to death"—that is certainly not a humane way to "let a child die."

A nurse in Boca Raton, Florida wrote:

> I am an RN with a speciality in maternal-child health. In the past few years I have had to witness the deaths of innocent children in hospitals where a decision was

> made not to continue with medical care and assistance.

Another nurse wrote:

> As a nurse (RN) in a neonatal ICU, I feel compelled to write and voice my support of the "Baby Doe rule" now proposed. . . . Many doctors and nurses openly support withholding or withdrawing medical care. . . . Due to the ethics of the medical director of the unit, this has only been done once or twice to my knowledge. I would report any cases of neglect I knew of if this number and service were available. . . . An outside third party is needed to police the cases. Please allow some method of reporting and investigating these babies' cases to be available.

From a nurse in San Diego, California came the following comment:

> [A]s a practicing registered nurse myself, I believe such regulations permit nurses and staff to act in a patient's best interest—life itself!—without fear of harrassament and possible job loss.

In addition, some commenters who opposed the proposed rule appeared to acknowledge that there is a risk that handicapped infants will not receive medically beneficial treatment. For example, the American Society of Law and Medicine, a national, nonprofit professional association, stated:

> There can be no question that some decisions to end life-sustaining care for newborns have been made inappropriately, even if the frequency of this problem has not been established.

Another example of this is the comment by the chairman of the division of pediatrics of a hospital in Illinois:

> We are acutely aware that handicapped individuals (*not* must handicapped newborns) are systematically discriminated against in our society. We are also acutely aware that we, like virtually all members of our society, are guilty of having prejudicial beliefs and attitudes about the handicapped. That pediatricians and other health care providers have acted on these negative beliefs and attitudes should come as no surprise. That parents, at least in the initial phase of their relationship with a handicapped newborn, should wish to be spared what is perceived as a burden or even wish that the infant had never been born should come as no shock.
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> * * * * *
>
> We wholeheartedly agree that in the past these obviously critically important decisions have not been accorded the degree of reflection and care they are due. Given the wide range of possible technological interventions now possible: given the changing conception of the appropriate role of physician and parents in such decisions: and given the need for public accountability for such decisions—we support the idea that the manner in which such decisions have been made in the past needs critical re-examination.

Another example is the comment of the American Academy of Pediatrics:

> The traditional method of a single physician making such judgment [regarding treatment], without exposure to other persons having additional facts, experience, and points of view, may lead to decisions, which, in retrospect, cannot be justified.

Response

The Department believes these comments provide additional support for the Department's conclusions that available evidence indicates there are cases in which handicapped infants are at risk of having life-sustaining, nourishment or medically beneficial treatment withheld solely on the basis of their present or anticipated physical or mental impairments, and that this evidence constitutes a substantial foundation for the establishment of basic procedural mechanisms to facilitate enforcement of section 504.

OCR Investigations to Date

Another argument made by a number of commenters to support criticisms of the adequacy of the factual basis for the proposed rule was that the experience of the Office for Civil Rights to date in connection with section 504 enforcement activities relating to health care for handicapped infants indicate there is no significant evidence of a problem that the rule could reasonably be designed to deal with. As stated by the American Hospital Association:

> The total absence of verifiable violations, notwithstanding hundreds of hotline calls, also compels the conclusion that either this mechanism is not an effective means to meet any alleged need or, as we believe to be the case, the violations that have been described are not occurring. In either case, a federal regulation is unnecessary.

Response

Rather than support the argument that there is no need for section 504 applicability or enforcement in connection with health care for handicapped infants, the OCR experience to date provides additional evidence that the assumption that handicapped infants will receive medically beneficial treatment is not always justified.

First, it must be noted that the vast majority of the several hundred calls made to the Department were not for the purpose of reporting suspected violations of section 504. Rather, the vast majority of calls were for administrative purposes, such as hospital officials asking questions about the provisions of the March interim final rule, individuals acting on their apparent curiosity to see if anyone would answer the telephone, and other peripheral matters. It should also be noted that the Department's experience under the interim final rule does not provide an adequate basis to make conclusive judgements in any direction because the rule was only in effect for about three weeks, from March 22 until April 14, the day Judge Gesell declared it invalid.

Following is a summary of the Infant Doe cases handled to date, and current as of December 1, 1983.

1. *Bloomington, Indiana.* Investigation into April 1982, death of infant with Down's syndrome and esophageal atresia from whom surgery was withheld on the instructions of the parents. An investigation, delayed due to difficulties in obtaining information sealed by court order, has been conducted. Final administrative action has not yet been taken.

2. *Robinson, Illinois.* May 14, 1982 complaint that hospital (at the parents' request) failed to perform necessary surgery on an infant born with myelomeningocele. Prompt on-site investigation was conducted, involving OCR, the Justice Department and the state child protective services agency. The parents refused consent for surgery; the hospital referred the matter to state authorities, who accepted custody of the infant and arranged for surgery and adoption. The care provided to the infant while these actions were taken was in compliance with section 504. Finding: no violation.

3. *Madison, Wisconsin.* May 7, 1982, complaint that two infant survivors of abortions may have been denied treatment. On-site investigation revealed that two infants, of 26 and 22 weeks gestation, were born alive following abortions; life-saving procedures were applied: neither infant could survive due to extreme prematurity. Finding: no violation.

4. *Kettering, Ohio.* July 26, 1982, complaint that an infant with spina bifida and hydrocephalus was not being treated. Immediate on-site investigation revealed that surgery to correct the spina bifida condition was not performed immediately because the infant had medical complications. Surgery was performed after the infant's condition stabilized. The hospital provided all proper treatment. Finding: no violation.

5. *Barrington, Illinois.* September 17, 1982, complaint that a multi-handicapped infant was not receiving needed treatment. Immediate on-site investigation determined that given the nature and severity of the problems, there were no procedures or services which could have been provided which might have changed or otherwise

influenced the outcome for this infant, who died for days after birth. Finding: no violation.

6. *New Haven, Connecticut.* October 12, 1982, complaint (referred from the Department of Justice) that hospital engaged in a pattern and practice of denying medical treatment to handicapped infants. The complaint was included in a compliance review, already in progress. The investigation has been expanded to include several cases involving other Connecticut hospitals. The investigation, which has included review of hundreds of medical files, has not been completed.

7. *Tulsa, Oklahoma.* December 7, 1982, complaint that a baby was being deliberately dehydrated. Immediate on-site investigation determined that the infant had hydranencephaly (complete or almost complete absence of cerebral hemispheres) and transposition of the great vessels (reversal of main vessels into heart); notwithstanding all proper care, the severity of the anomalies made the prognosis very pessimistic. Finding: no violation.

8. *Duarte, California.* January 10, 1983, complaint that the hospital denied the complainant's son admission to the hospital for a bone marrow transplant solely because of his handicapping condition, Down's syndrome. An investigation has been conducted. Administrative action has not been completed.

9. *Austin, Texas.* January 17, 1983, complaint that newborn babies with serious birth defects have not received proper care. An investigation has been conducted. Administrative action has not been completed.

10. *Lansing, Michigan.* January 24, 1983, complaint that a handicapped infant born to a surrogate mother was treated for a streptococci infection over the objections of the father who had told the hospital not to care for the child. OCR inquiry determined the hospital took immediate steps to obtain an appropriate court order to assure that needed treatment was provided, notwithstanding objections from the father. Finding: no violation.

11. *San Antonio, Texas.* March 2, 1983, complaint that deaths of a number of infants at two hospitals may have been related to discriminatory withholding of care. OCR investigation postponed at request of District Attorney assisting in grand jury criminal investigation.

12. *Houston, Texas.* March 10, 1983, complaint that five infants were denied proper care in a neonatal intensive care unit. The investigation has not been completed.

13. *Jackson, Michigan.* March 14, 1983, complaint from a mother that her son, who had Down's syndrome, died as a result of improper treatment. An investigation has been conducted. Administrative action not completed.

14. *Odessa, Texas.* March 18, 1983, hotline complaint that the hospital had failed to provide adequate medical care to a premature infant who died in 1982. On-site investigation and review of medical records by OCR medical consultant found that the infant, born March 18, 1982, after a 25–28-week gestation period, suffered from extreme immaturity, and died March 20, 1982. Finding: no violation.

15. *Nashville, Tennessee.* March 22, 1983, hotline complaint that an infant had been denied sustenance for three days. Immediate contact revealed the infant was not a patient at the facility and the alleged attending physician was not a member of the attending or resident medical staff. This was verified by the patient census data, the facility's physician roster, and contact with the county medical society. This case was administratively closed due to an insufficient complaint.

16. *Nashville, Tennessee.* March 22, 1983, anonumous hotline complaint that 10 childern were not receiving adequate medical treatment. Immediate on-site investigation, including an OCR medical consultant, determined that no child was in imminent danger; all children were receiving nutritional sustenance; and all children were receiving proper care. Finding: no violation.

17. *Fayette, Alabama.* March 22, 1983, anonymous hotline complaint that a handicapped infant was denied nourishment and allowed to die in an Alabama hospital in December 1982. The caller could provide no other information. Investigation has been conducted. Administrative action awaiting report from medical consultant.

18. *Waxahachie, Texas.* March 23, 1983, anonymous hotline complaint that between Christmas and February, a premature infant was denied treatment and allowed to die at a hospital in Texas. An investigation has been conducted. Administrative action not yet completed.

19. *Baltimore, Maryland.* March 23, 1983, hotline complaint that a premature infant was not being provided nourishment and heat. An immediate on-site investigation determined that the infant, weight 1 lb., ½ ounce at birth, was previable; the infant died several hours after birth; the infant had no congenital malformations or anomalies. Final administrative action on this case has not yet been taken.

20. *Newark, New Jersey.* March 27, 1983, anonmous hotline complaint that a premature infant, born as a result of a third trimester abortion, was not receiving adequate care. Immediate on-site investigation reveled that the premature infant weighed about 700 grams, and showed few signs of life. The infant was aggressively resuscitated, placed on intravenous feeding, and provided other life supporting treatment. Appropriate care was being provided. Finding: no violation.

21. *Rochester, New York.* March 29, 1983, hotline complaint that Siamese twin infants were being denied treatment. Immediate on-site investigation determined that a team specialists examined the infants and concluded the conjoined female infant would not survive any attempt to separate them. Full intensive care was provided. The infants were placed on a respirator and given antibiotics, fluid and the necessary nutrition. At the time of the on-site, March 29, 1983, it was determined that there was no basis for seeking emergency remedial action. Final administrative action has not yet been completed.

22. *Seattle., Washington.* March 30, 1983, hotline complaint that an infant was being denied food and water and would not live much longer than a day or two. The caller had no identifying or other information. Immediate on-site inquiry determined there were no infants at the facility meeting the description of the complaint. The case was administratively closed due to insufficient complaint.

23. *Miami, Florida.* April 4, 1983, hotline complaint alleging (based upon information in the newspaper) parents of a premature infant and the attending physician decided not to allow the infant to be resuscitated. Immediate inquiry determined the infant had died prior to receipt of the complaint. The premature infant had multiple catastrophic conditions, including complete liquefaction of the brain. Final administrative action awaiting report of medical consultant.

24. *Decatur, Alabama.* April 6, 1983, hotline complaint from a parent that her child's condition was misdiagnosed by a particular physician during a 2½ year period. Inquiry determined that the child suffers from food allergies; the prognosis is excellent, the child at one time was believed, apparently erroneously, to be retarded. This case was administratively closed because the inquiry failed to reveal ilnformation suggesting a possible violation of section 504.

25. *Melrose Park, Illinois.* April 8, 1983, anonymous hotlilne complaint. The caller provided no details concerning the infant's condition or treatment.

Immediate telephone inquiry discovered no information to suggest a section 504 violation. This case was administratively closed due to an insufficient complaint.

26. *Charlotte, North Carolina.* April 10, 1983, hotline complaint that a premature infant died in July 1979 due to withholding of treatment. The caller could not provide any other information. Due to the length of time since the alleged discriminatory act and the lack of specific information, this case was administratively closed due to an insufficient complaint.

27. *Hyde Park, New York.* April 13, 1983, anonymous hotline complaint that the hospital would have let a baby with Down's syndrome die if the parents had not been aggressive and insisted on care being provided. The caller could provide no identifying information. This case was administratively closed due to an insufficient complaint.

28. *Coquille, Oregon.* April 13, 1983, hotline complaint that parents of a handicapped infant and the attending physician were going to withhold all treatment. Immediate on site investigation, including medical consultant's review of medical records, determined the infant had a severe congenital central nervous system defect incompatible with life and not amenable to surgical correction; hospital provided supportive care and attempted to provide fluid orally, but did not attempt to provide intravenous fluids or arrange immediate transfer to a tertiary level neonatal intensive care unit for more specialized evaluations. The OCR medical consultant and the specialists at the tertiary care facility to which the infant was transferred three days after birth concluded that no course of treatment which was available would have avoided imminent death of this infant; the most that could have been expected from more aggressive care would have been to prolong the act of dying. The infant died 10 days after birth. Finding: no violation.

29. *Athens, Tennessee.* April 18, 1983, anonymous hotline complaint that an infant born at 28 weeks gestation was denied treatment and nourishment and allowed to die at a Tennessee hospital. The caller could give no identifying information. Investigation has been conducted. Administrative action awaiting report of medical consultant.

30. *Shreveport, Louisiana.* April 20, 1983, hotline complaint that a particular physician at the hospital certified three infants born alive as stillborn and refused to provide care to another infant. Investigation, including medical consultant review, found no medically beneficial treatment was withheld. Finding: no violation.

31. *Dayton, Ohio.* April 29, 1983, anonymous hotline complaint that an infant, identity unknown, weighing one pound and eight ounces was denied treatment and died. Inquiry revealed the deceased infant was premature (22 weeks gestation) and immature (organs were not developed); the infant had no anomalies; the hospital attempted to administer oxygen but the lungs were too small to function; no medically beneficial treatment was withheld. This case was administratively closed due to the lack of information suggesting possible violation of section 504.

32. *Los Angeles, California.* May 17, 1983, complaint that infant, believed stillborn, lived several hours and may not have received proper care. Administrative action has not been completed.

33. *Daytona Beach, Florida.* May 19, 1983, hotline complaint that an infant with spina bifida may not be receiving medical treatment. Immediate contact with hospital and state agency and prompt on-site investigation indicated that the parents did not consent to surgery for the infant; on May 18, eight days after birth, the state agency obtained a court order to provide surgery, which was performed May 22, 1983. An investigation has been conducted. Administrative action awaits report of medical consultant.

34. *Baton Rouge, Louisiana.* May 23, 1983, hotline complaint that medical services were denied a premature infant, who died soon after birth. Investigation has been conducted. Administrative action has not been completed.

35. *Colorado Springs, Colorado.* June 21, 1983, hotline complaint from a nurse that an infant with myelomeningocele and paralyzed vocal chords was being denied necessary surgery. Immediate on-site investigation indicated substantial uncertainty on whether treatment for the myelomeningocele would be provided immediately; physicians were providing nutrition and supportive care and were awaiting the results of several tests on the infant. During the afternoon, hospital personnel were advised that an on-site investigation would be initiated that evening; that the state child protective services agency would be asked to also investigate; and that OCR would notify the Justice Department of the investigation. Also during the afternoon, the OCR medical consultant discussed the case with the attending physician. That evening corrective surgery was performed on the myelomeningocele. Investigation, including review by medical consultant, determined that no medically beneficial treatment was withheld on the basis of the infant's handicap. Finding: no violation.

36. *Brooklyn, New York.* June 23, 1983, complaint that premature infant who died in 1981 did not receive proper care. An investigation was conducted. Administrative action awaits report of medical consultant.

37. *Atlanta, Georgia.* June 27, 1983, hotline complaint that an infant, identity unknown, born with multiple anomalies was in a life-threatening situation because the doctors were planning to cease treatment of the infant. On-site investigation, June 28, indicated the premature infant, who weighed 950 grams at birth, received aggressive treatment, but the prognosis was not optimistic. At the time of the on-site investigation, it was determined there was no basis to seek emergency remedial action. Final administrative action is awaiting written report from medical consultant.

38. *Medford, Oregon.* July 7, 1983, anonymous hotline complaint that two infants died in 1982 because of improper medical treatment. The investigation has not been completed.

39. *Pinehurst, North Carolina.* July 21, 1983, hotline complaint that a three-week old infant with spina bifida and hydrocephalus would not live if surgical treatment was not provided. Immediate inquiry determined the appropriate surgery was performed July 8, 1983. Final administrative action has not been concluded.

40. *San Francisco, California.* August 2, 1983, hotline complaint that an infant with a cleft palate and heart defect was allowed to die at a California hospital in May 1979. The caller stated that a malpractice lawsuit is pending. The investigation has not been completed.

41. *Falls Church, Virginia.* August 9, 1983, hotline complaint that a baby, identity unknown, with possible brain damage, no ears or eyes, would not be given nourishment. A meeting with hospital officials failed to identify an infant meeting the description given by the complainant. An infant with somewhat similar circumstances was described; no information concerning this infant suggested a lack of appropriate care. Complainant refused to accept OCR calls seeking further information. This case was administratively closed due to an insufficient complaint.

42. *Wichita, Kansas.* August 11, 1983, complaint that infant whose body was discovered at incinerator site may have been denied proper treatment. An investigation has been conducted.

Administrative action has not been completed.

43. *Lincoln, Nebraska.* August 25, 1983, hotline complaint that two premature infants did not receive appropriate care and died. The investigation has not been completed.

44. *Boynton Beach, Florida.* September 20, 1983, hotline complaint that two handicapped infants were allowed to die immediately following birth. The investigation has not been completed.

45. *Norfolk, Virginia.* September 21, 1983, complaint that infant born alive following an abortion was not being fed or treated. Inquiry determined infant died September 20, 1983. Final administrative action has not been completed.

46. *Boise, Idaho.* September 30, 1983, hotline complaint that an abandoned premature infant with no brain tissue might be withdrawn from life support. Immediate inquiry determined the State child protective services agency had obtained custody of the infant and had no plans to discontinue life support. Final administrative action has not been completed.

47. *Philadelphia, Pennsylvania.* October 16, 1983, hotline complaint that infant, age approximately six weeks, with spina bifida, who received surgery, was not receiving appropriate follow-up care. Inquiry initiated October 16. Decision made that circumstances did not suggest need for immediate remedial action. Final administrative action has not been completed.

48. *Long Island, New York.* October 19, 1983, complaint, based on newspaper article, that infant with spina bifida not receiving surgery due to refusal of parents to consent; legal proceedings has been initiated in State court. Inquiry initiated October 19. On October 27, HHS asked Department of Justice to commence legal action to overcome refusal of hospital to permit review of pertinent records. On November 2, legal action was commenced. On November 17, district court ruled against the government. Appeal filed November 18.

49. *Phoenix, Arizona.* November 7, 1983 anonymous hotline complaint that infant with spina bifida and other conditions not receiving surgery. Immediate inquiry initiated; records obtained; OCR medical consultant discussed case with attending physician and hospital review committee. Decision made not to refer case to Justice Department for emergency remedial action. Final administrative action not yet completed.

The Department believes three of these cases demonstrate the utility of the procedural mechanisms called for in the final rules. In the Robinson, Illinois case (listed as case 2, above), for example, the involvement of the state child protective services agency, working in cooperation with HHS and the Justice Department, was the most important element in bringing about corrective surgery for the infant. The state agency received a report from the hospital administrator pursuant to the state child protective services statute. Had there been no governmental involvement in the case, the outcome might have been much less favorable. Media reports one year later indicate the child's development was proceeding very well, with leg braces adequately compensating for the child's impairment.

In the Daytona Beach, Florida case (listed as case 33, above), action by the state child protective services agency, like that called for in the final rules, brought about needed corrective surgery. Without this action, the infant might have died or suffered more severe impairments.

In the Colorado Springs, Colorado case (listed as case 35, above) the prompt involvement of HHS, acting upon a complaint from a nurse, may have contributed to the decision to provide corrective surgery. Because the decisionmaking process was in progress at the time the OCR inquiry began, it is impossible to say the surgery would not have been provided without this involvement. However, the involvement of OCR and the OCR medical consultant was cooperatively received by the hospital and apparently constructive.

Although no case has resulted in a finding of discriminatory withholding of medical care, the Department believes these cases provide additional documentation of the need for governmental involvement and the appropriateness of the procedures established by the final rules.

E. OTHER ISSUES

Self-Evaluation

Among the questions on which the July 5 notice of proposed rulemaking solicited comments was question 1:

> Should recipients providing health care services to infants be required to perform a self-evaluation, pursuant to 45 CFR 84.6(c)(1), with respect to their policies and practices concerning health services to handicapped infants?

A number of commenters expressed support for this requirement. Some commenters expressed the view that self-evaluations would be helpful and should be conducted, but they should not be a federal regulatory mandate. Some commenters suggested that if this were to be a requirement, it should be through mechanisms other than section 504, such as voluntary accreditation standards or Medicare conditions of participation.

Some commenters opposed a self-evaluation requirement on the grounds it would likely be unproductive. For example:

> Americans United for Life is skeptical of any approach to the enforcement of section 504 that relies on the cooperation of those being regulated. Encouraging hospitals to perform "*self*-evaluation" is not likely to lead to *accurate* evaluation.

Response

The Department has not adopted a self-evaluation requirement as part of the final rules. The Department believes this function will be most effectively carried out in connection with the activities of Infant Care Review Committees encouraged by the final rules, and therefore will not seek to impose uniform standards for self-evaluations.

Information to Parents

Among the questions on which the July 5 notice of proposed rulemaking solicited comments was question 2:

> Should such recipients be required to identify for parents of handicapped infants born in their facilities those public and private agencies in the geographical vicinity that provide services to handicapped infants?

A great many commenters expressed support for such a requirement on the ground that before parents are put into a position of having to make very difficult decisions concerning care for their handicapped child, the parents should be aware of the health and social services agencies and organizations and parental support groups available in the community. Other commenters opposed this requirement. Some commenters expressed the view that hospitals should provide this information as part of their own policies and procedures, but that it would be counterproductive to seek to impose rigid, uniform regulatory requirements in this regard.

Among those supporting such a requirement was the Spina Bifida Association of America (SBAA):

> The SBAA strongly supports such a requirement; it might be the most important influential aspect of the entire regulation.
>
> Parents of a newborn spina bifida child are expected to make rational life and death decisions when what was expected to be a joyous time has instead become an occasion for confronting the concerns of the unknown. The decisions must be made quickly and under great stress. Dr. Rosalyn Darling, a member of SBAA's Professional Advisory Committee, has written that decisions are often made by physicians and individuals who have very little contact with the

disabled community, consequently, decisions concerning treatment are often "stacked" against the newborn with a problem. Parents naturally turn to their physician for guidance, but he or she may have only outdated and unwarrantedly pessimistic information about spina bifida. Even if the physician is well-informed about the available treatment, he or she is rarely aware of the supportive services in the community or equipped to give the support and counselling that others who have gone through the same experience can't provide.

Clearly, new parents of a disabled child need the names of agencies and support groups available to assist the family unit. Other parents who have gone through the same situation can then share their knowledge of the disability and its treatment and give comfort and assistance.

The American Speech-Language-Hearing Association, which represents 39,000 speech-language pathologists and audiologists nationwide, stated:

> [P]arents and physicians are largely unaware of what educational, habilitative, and rehabilitative services are available for handicapped children, how much success handicapped children receiving these services can have, the obligation of states to educate handicapped children, the extent of research now going on regarding handicapped children, and other federal, state and local governmental commitments to the handicapped. Unfortunately, physicians have all that they can do to maintain currency with medical information and are, therefore, frequently ill-informed as to what can be done for handicapped infants.
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> * * * * *
>
> Recipients should be required to provide complete information to the parent about the appropriate handicap. This would include not only identification of public and private agencies that provide services to handicapped infants, but (1) detailed information on the handicap itself; (2) discussion of the educational and rehabilitation potential; (3) discussion of alternative care options such as foster homes, adoption, etc.; (4) identification of parent support groups; and (5) discussion of expectations for a self-sufficient future life. In providing the required information the recipient should use individuals knowledgeable about the handicap, including professionals, associations and parents of handicapped children. For example, the American Speech-Language-Hearing Association and its consumer affiliate, the National Association of Hearing and Speech Action (NAHSA) maintains a Help line (800-638-8255) that can be used to obtain information on (1) speech-language pathology and audiology services available in any area of the United States, (2) speech, language and hearing disorders, and (3) other agencies serving the communicatively handicapped. NAHSA provides informational brochures. . . . Many professional associations have similar documents that would be helpful to recipients.

Among those opposing a requirement that recipients provide information to parents was Georgetown University Hospital, Washington, D.C. As an alternative, the hospital proposed:

> DHHS should undertake the responsibility of providing a federal office charged with the task of identifying for parents of handicapped children those public and private agencies in the geographical vicinity of the parent's residence that provide service of handicapped infants, and for providing the necessary financial assistance to acquire such services. Hospitals should be required to furnish parents with a telephone number, and/or address of this federal office.

Response

The Department believes it is extremely important for parents of handicapped newborn infants to receive detailed information on the availability of health and social services for handicapped children in the communities. However, the Department has concluded the most effective way to advance this goal is not through an attempt to impose detailed regulatory requirements that would be very difficult to monitor and enforce.

Rather, the Department has undertaken several initiatives, discussed above in the preamble, to improve the furnishing of information to parents. In addition, this should be a central focus of the activities of the Infant Care Review Committees, which, under the model set forth in the final rules, include participation by representatives of disability groups or disability experts.

VI. Regulatory Information

Severability

It is the Secretary's intent that should any subsection, paragraph, clause, or provision of this rule be declared by a court of competent jurisdiction to be invalid, the remainder of the rule, not expressly so declared invalid, shall continue in effect.

Regulatory Impact Analysis

This proposed rule has been reviewed under Executive Order 12291. It is not a major rule as defined by the Order because it does not have an effect on the economy of $100 million or more or meet the other definitional criteria contained in the Order, and thus does not require a regulatory impact analysis.

Regulatory Flexibility Analysis

The Regulatory Flexibility Act (Pub. L. 96–354) requires the Federal government to anticipate and reduce the impact of rules and paperwork requirements on small businesses and other small entities. For each rule with a "significant impact on a substantial number of small entities" an analysis must be prepared describing the rule's impact on small entities.

The Secretary certifies that the final rules do not have a significant impact on a substantial number of small entities. As it relates to hospitals, the primary requirement of the final rules is to post an informational notice, which has no significant impact on the hospitals. The requirements concerning expedited access to records and expedited action to effect compliance also, as explained above, have no significant impact. Requirements in the final rules relating to state child protective services agencies have no substantial impact on those agencies, because those requirements, as explained above, are fully consistent with normal procedures of those agencies and existing regulatory requirements.

Matters addressed in the guidelines included in the final rules are not requirements of the rules. They reflect interpretations and procedures of the Department pursuant to the statute, existing regulations, and existing procedures.

Therefore, a regulatory flexibility analysis is not required.

Paperwork Reduction Act

Section 84.55(c) of the final rules contains information collection requirements. These requirements were submitted to the Office of Management and Budget for review under section 3504(h) of the Paperwork Reduction Act of 1980, and approved for use through September 30, 1986. The OMB No. is 0990–0114.

Department of Justice Review

Pursuant to Executive Order 12250 these final rules have been reviewed and approved by the Department of Justice.

List of Subjects in 45 CFR Part 84

Civil rights, Education of handicapped, Handicapped, Physically handicapped.

Dated: December 30, 1983.

Approved:

Margaret M. Heckler,

Secretary.

PART 84—[AMENDED]

The authority citation for Part 84 is as follows:

Authority: Sec. 504, Rehabilitation Act of 1973, Pub. L. 93-112, 87 Stat. 394 (29 U.S.C. 794); sec. 111(a), Rehabilitation Act Amendments of 1974, Pub. L. 93–516, 88 Stat. 1619 (29 U.S.C. 706); sec. 606, Education of the Handicapped Act (20 U.S.C. 1405), as amended by Pub. L. 94-142, 89 Stat. 795; sec. 321, Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and

Rehabilitation Act of 1970, 84 Stat. 182 (42 U.S.C. 4581), as amended, sec. 497, Drug Abuse Office and Treatment Act of 1972, 86 Stat. 78 (21 U.S.C. 1174), as amended.

For the reasons set forth in the preamble:

1. 45 CFR Part 84 is amended by inserting after § 84.54 the following new § 84.55:

§ 84.55 Procedures relating to health care for handicapped infants.

(a) *Infant Care Review Committees.* The Department encourages each recipient health care provider that provides health care services to infants in programs receiving Federal financial assistance to establish an Infant Care Review Committee (ICRC) to assist the provider in delivering health care and related services to infants and in complying with this part. The purpose of the committee is to assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases. While the Department recognizes the value of ICRC's in assuring appropriate medical care to infants, such committees are not required by this section. An ICRC should be composed of individuals representing a broad range of perspectives, and should include a practicing physician, a representative of a disability organization, a practicing nurse, and other individuals. A suggested model ICRC is set forth in paragraph (f) of this section.

(b) *Posting of informational notice.* (1) Each recipient health care provider that provides health care services to infants in programs or activities receiving Federal financial assistance shall post and keep posted in appropriate places an informational notice.

(2) The notice must be posted at location(s) where nurses and other medical professionals who are engaged in providing health care and related services to infants will see it. To the extent it does not impair accomplishment of the requirement that copies of the notice be posted where such personnel will see it, the notice need not be posted in area(s) where parents of infant patients will see it.

(3) Each health care provider for which the content of the following notice (identified as Notice A) is truthful may use Notice A. For the content of the notice to be truthful: (i) The provider must have a policy consistent with that stated in the notice; (ii) the provider must have a procedure for review of treatment deliberations and decisions to which the notice applies, such as (but not limited to) an Infant Care Review Committee; and (iii) the statements concerning the identity of callers and retaliation are truthful.

Notice A:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

It is the policy of this hospital, consistent with Federal law, that, nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify designated hospital contact point and telephone number] or

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free; available 24 hours a day; TDD capability).

The identity of callers will be held confidential. Retaliation by this hospital against any person for providing information about possible noncompliance is prohibited by this hospital and Federal regulations.

(4) Health care providers other than those described in paragraph (b)(3) of this section must post the following notice (identified as Notice B):

Notice B:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

Federal law prohibits discrimination on the basis of handicap. Under this law, nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, applies to programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free; available 24 hours a day; TDD capability).

The identity of callers will be held confidential. Federal regulations prohibit retaliation by this hospital against any person who provides information about possible violations.

(5) The notice may be no smaller than 5 by 7 inches, and the type size no smaller than that generally used for similar internal communications to staff. The recipient must insert the specified information on the notice it selects. Recipient hospitals in Washington, D.C. must list 863-0100 as the telephone number for HHS. No other alterations may be made to the notice. Copies of the notices may be obtained from the Department of Health and Human Services upon request, or the recipient may produce its own notices in conformance with the specified wording.

(c) *Responsibilities of recipient state child protective services agencies.* (1) Within 60 days of the effective date of this section, each recipient state child protective services agency shall establish and maintain in written form methods of administration and procedures to assure that the agency utilizes its full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants. These methods of administration and procedures shall include:

(i) A requirement that health care providers report on a timely basis to the state agency circumstances which they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants;

(ii) A method by which the state agency can receive reports of suspected unlawful medical neglect of handicapped infants from health care providers, other individuals, and the Department on a timely basis;

(iii) Immediate review of reports of suspected unlawful medical neglect of handicapped infants and, where appropriate, on-site investigation of such reports;

(iv) Provision of child protective services to such medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the provision of necessary nourishment and medical treatment; and

(v) Timely notification to the responsible Department official of each report of suspected unlawful medical neglect involving the withholding, solely on the basis of present or anticipated physical or mental impairments, of treatment or nourishment from a handicapped infant who, in spite of such impairments, will medically benefit from the treatment or nourishment, the steps taken by the state agency to investigate such report, and the state agency's final disposition of such report.

(2) Whenever a hospital at which an infant who is the subject of a report of suspected unlawful medical neglect is being treated has an Infant Care Review Committee (ICRC) the Department encourages the state child protective services agency to consult with the ICRC in carrying out the state agency's authorities under its state law and methods of administration. In developing its methods of

administration and procedures, the Department encourages child protective services agencies to adopt guidelines for investigations similar to those of the Department regarding the involvement of ICRC's.

(The provisions of § 84.55(c) have been approved by the Office of Management and Budget pursuant to the Paperwork Reduction Act. The OMB No. is 0990-0114.)

(d) *Expedited access to records.* Access to pertient records and facilities of a recipient pursuant to 45 CFR 80.6(c) (made applicable to this part by 45 CFR 84.61) shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

(e) *Expedited action to affect compliance.* The requirement of 45 CFR 80.8(d)(3) pertaining to notice to recipients prior to the initiation of action to effect compliance (made applicable to this part by 45 CFR 84.61) shall not apply when, in the judgment of the responsible Department official, immediate action to effect compliance is necessary to protect the life or health of a handicapped individual. In such cases the recipient will, as soon as practicable, be given oral or written notice of its failure to comply, of the action to be taken to effect compliance, and its continuing opportunity to comply voluntarily.

(f) *Model Infant Care Review Committee.* Recipient health care providers wishing to establish Infant Care Review Committees should consider adoption of the following model. This model is advisory. Recipient health care providers are not required to establish a review committee or, if one is established, to adhere to this model. In seeking to determine compliance with this part, as it relates to health care for handicapped infants, by health care providers that have an ICRC established and operated substantially in accordance with this model, the Department will, to the extent possible, consult with the ICRC.

(1) *Establishment and purpose.* (i) The hospital establishes an Infant Care Review Committee (ICRC) or joins with one or more other hospitals to create a joint ICRC. The establishing document will state that the ICRC is for the purpose of facilitating the development and implementation of standards, policies and procedures designed to assure that, while respecting reasonable medical judgments, treatment and nourishment not be withheld, solely on the basis of present or anticipated physical or mental impairments, from handicapped infants who, in spite of such impairments, will benefit medically from the treatment or nourishment.

(ii) The activities of the ICRC will be guided by the following principles:

(A) The interpretative guidelines of the Department relating to the applicability of this part to health care for handicapped infants.

(B) As stated in the "Principles of Treatment of Disabled Infants" of the coalition of major medical and disability organizations, including the American Academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Association for Retarded Citizens, Down's Syndrome Congress, Spina Bifida Association, and others:

> When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.
>
> It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.
>
> In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

(C) As stated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

> This [standard for providing medically beneficial treatment] is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.

(iii) The ICRC will carry out its purposes by:

(A) Recommending institutional policies concerning the withholding or withdrawal of medical or surgical treatments to infants, including guidelines for ICRC action for specific categories of life-threatening conditions affecting infants;

(B) Providing advice in specific cases when decisions are being considered to withhold or withdraw from infant life-sustaining medical or surgical treatment; and

(C) Reviewing retrospectively on a regular basis infant medical records in situations in which life-sustaining medical or surgical treatment has been withheld or withdrawn.

(2) *Organization and staffing.* The ICRC will consist of at least 7 members and include the following:

(i) A practicing physician (e.g., a pediatrician, a neonatologist, or a pediatric surgeon),

(ii) A practicing nurse,

(iii) A hospital administrator,

(iv) A representative of the legal profession,

(v) A representative of a disability group, or a developmental disability expert,

(vi) A lay community member, and

(vii) A member of a facility's organized medical staff, who shall serve as chairperson.

In connection with review of specific cases, one member of the ICRC shall be designated to act as "special advocate" for the infant, as provided in paragraph (f)(3)(ii)(E) of the section. The hospital will provide staff support for the ICRC, including legal counsel. The ICRC will meet on a regular basis, or as required below in connection with review of specific cases. It shall adopt or recommend to the appropriate hospital official or body such administrative policies as terms of office and quorum requirements. The ICRC will recommend procedures to ensure that both hospital personnel and patient families are fully informed of the existence and functions of the ICRC and its availability on a 24-hour basis.

(3) *Operation of ICRC—*(i) *Prospective policy development.* (A) The ICRC will develop and recommend for adoption by the hospital institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions. These will include guidelines for management of specific types of cases or diagnoses, for example, Down's syndrome and spina bifida, and procedures to be followed in such recurring circumstances as, for example, brain death and parental refusal to consent to life-saving treatment. The

hospital, upon recommendation of the ICRC, may require attending physicians to notify the ICRC of the presence in the facility of an infant with a diagnosis specified by the ICRC, e.g., Down's syndrome and spina bifida.

(B) In recommending these policies and guidelines, the ICRC will consult with medical and other authorities on issues involving disabled individuals, e.g., neonatologists, pediatric surgeons, county and city agencies which provide services for the disabled, and disability advocacy organizations. It will also consult with appropriate committees of the medical staff, to ensure that the ICRC policies and guidelines build on existing staff by-laws, rules and regulations concerning consultations and staff membership requirements. The ICRC will also inform and educate hospital staff on the policies and guidelines it develops.

(ii) *Review of specific cases.* In addition to regularly scheduled meetings, interim ICRC meetings will take place under specified circumstances to permit review of individual cases. The hospital will, to the extent possible, require in each case that life-sustaining treatment be continued, until the ICRC can review the case and provide advice.

(A) Interim ICRC meetings will be convened within 24 hours (or less if indicated) when there is disagreement between the family of an infant and the infant's physician as to the withholding or withdrawal of treatment, when a preliminary decision to withhold or withdraw life-sustaining treatment has been made in certain categories of cases identified by the ICRC, when there is disagreement between members of the hospital's medical and/or nursing staffs, or when otherwise appropriate.

(B) Such interim ICRC meetings will take place upon the request of any member of the ICRC or hospital staff or parent or guardian of the infant. The ICRC will have procedures to preserve the confidentiality of the identity of persons making such requests, and such persons shall be protected from reprisal. When appropriate, the ICRC or a designated member will inform the requesting individual of the ICRC's recommendation.

(C) The ICRC may provide for telephone and other forms of review when the timing and nature of the case, as identified in policies developed by the ICRC, make the convening of an interim meeting impracticable.

(D) Interim meetings will be open to the affected parties. The ICRC will ensure that the interests of the parents, the physician, and the child are fully considered, that family members have been fully informed of the patient's condition and prognosis; that they have been provided with a listing which describes the services furnished by parent support groups and public and private agencies in the geographic vicinity to infants with conditions such as that before the ICRC; and that the ICRC will facilitate their access to such services and groups.

(E) To ensure a comprehensive evaluation of all options and factors pertinent to the committee's deliberations, the chairperson will designate one member of the ICRC to act, in connection with that specific case, as special advocate for the infant. The special advocate will seek to ensure that all considerations in favor of the provision of life-sustaining treatment are fully evaluated and considered by the ICRC.

(F) In cases in which there is disagreement on treatment between a physician and an infant's family, and the family wishes to continue life-sustaining treatment, the family's wishes will be carried out, for as long as the family wishes, unless such treatment is medically contraindicated. When there is physician/family disagreement and the family refuses consent to life-sustaining treatment, and the ICRC, after due deliberation, agrees with the family, the ICRC will recommend that the treatment be withheld. When there is physician/family disagreement and the family refuses consent, but the ICRC disagrees with the family, the ICRC will recommend to the hospital board or appropriate official that the case be referred immediately to an appropriate court or child protective agency, and every effort shall be made to continue treatment, preserve the status quo, and prevent worsening of the infant's condition until such time as the court or agency renders a decision or takes other appropriate action. The ICRC will also follow this procedure in cases in which the family and physician agree that life-sustaining treatment should be withheld or withdrawn, but the ICRC disagrees.

(iii) *Retrospective record review.* The ICRC, at its regularly-scheduled meeting, will review all records involving withholding or termination of medical or surgical treatment to infants consistent with hospital policies developed by the ICRC, unless the case was previously before the ICRC pursuant to paragraph (f)(3)(ii) of this section. If the ICRC finds that a deviation was made from the institutional policies in a given case, it shall conduct a review and report the findings to appropriate hospital personnel for appropriate action.

(4) *Records.* The ICRC will maintain records of all of its deliberations and summary descriptions of specific cases considered and the disposition of those cases. Such records will be kept in accordance with institutional policies on confidentiality of medical information. They will be made available to appropriate government agencies, or upon court order, or as otherwise required by law.

Amendment to Table of Contents

2. The table of contents to 45 CFR Part 84 is amended by striking the designation of "84.55–84.60 [Reserved]" and by inserting in lieu thereof, the following:

Sec.
84.55 Procedures relating to health care for handicapped infants.
84.56–84.60 [Reserved]

3. 45 CFR Part 84 is amended by inserting after Appendix B the following new appendix:

Appendix C—Guidelines Relating to Health Care for Handicapped Infants

(a) *Interpretative guidelines relating to the applicability of this part to health care for handicapped infants.* The following are interpretative guidelines of the Department set forth here to assist recipients and the public in understanding the Department's interpretation of section 504 and the regulations contained in this part as applied to matters concerning health care for handicapped infants. These interpretative guidelines are illustrative; they do not independently establish rules of conduct.

(1) With respect to programs and activities receiving Federal financial assistance, health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.

(2) Futile treatment or treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant.

(3) In determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected.

(4) Section 504 and the provisions of this part are not applicable to parents (who are not recipients of Federal financial assistance). However, each recipient health care provider must in all aspects of its health care programs receiving Federal financial assistance provide health care and related services in a manner consistent with the requirements of section 504 and this part. Such aspects includes decisions on whether to report, as required by State law or otherwise, to the appropriate child protective services agency a suspected instance of medical neglect of a child, or to take other

action to seek review or parental decisions to withhold consent for medically indicated treatment. Whenever parents make a decision to withhold consent for medically beneficial treatment or nourishment, such recipient providers may not, solely on the basis of the infant's present or anticipated future mental or physical impairments, fail to follow applicable procedures on reporting such incidents to the child protective services agency or to seek judicial review.

(5) The following are examples of applying these interpretative guidelines. These examples are stated in the context of decisions made by recipient health care providers. Were these decisions made by parents, the guideline stated in section (a)(4) would apply. These examples assume no facts or complications other than those stated. Because every case must be examined on its individual facts, these are merely illustrative examples to assist in understanding the framework for applying the nondiscrimination requirements of section 504 and this part.

(i) Withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome when the withholding is based upon the anticipated future mental retardation of the infant and there are no medical contraindications to the surgery that would other wise justify withholding the surgery would constitute a discriminatory act, violative of section 504.

(ii) Withholding of treatment for medically correctable physical anomalies in children born with spina bifida when such denial is based on anticipated mental impairment paralysis or incontinence of the infant, rather than on reasonable medical judgments that treatment would be futile, too unlikely of success given complications in the particular case, or otherwise not of medical benefit to the infant, would constitute a discriminatory act, violative of section 504.

(iii) Withholding of medical treatment for an infant born with anencephaly, who will inevitably die within a short period of time, would not constitute a discriminatory act because the treatment would be futile and do no more than temporarily prolong the act of dying.

(iv) Withholding of certain potential treatments from a severely premature and low birth weight infant on the grounds of reasonable medical judgments concerning the improbability of success or risks of potential harm to the infant would not violate section 504.

(b) *Guidelines for HHS investigations relating to health care for handicapped infants.* The following are guidelines of the Department in conducting investigations relating to health care for handicapped infants. They are set forth here to assist recipients and the public in understanding applicable investigative procedures. These guidelines do not establish rules of conduct, create or affect legally enforceable rights of any person, or modify existing rights, authorities or responsibilities pursuant to this part. These guidelines reflect the Department's recognition of the special circumstances presented in connection with complaints of suspected life-threatening noncompliance with this part involving health care for handicapped infants. These guidelines do not apply to other investigations pursuant to this part, or other civil rights statutes and rules. Deviations from these guidelines may occur when, in the judgment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant.

(1) Unless impracticable, whenever the Department receives a complaint of suspected life-threatening noncompliance with this part in connection with health care for a handicapped infant in a program or activity receiving Federal financial assistance, HHS will immediately conduct a preliminary inquiry into the matter by initiating telephone contact with the recipient hospital to obtain information relating to the condition and treatment of the infant who is the subject of the complaint. The preliminary inquiry, which may include additional contact with the complainant and a requirement that pertinent records be provided to the Department, will generally be completed within 24 hours (or sooner if indicated) after receipt of the complaint.

(2) Unless impracticable, whenever a recipient hospital has an Infant Care Review Committee, established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the Department will, as part of its preliminary inquiry, solicit the information available to, and the analysis and recomendations of, the ICRC. Unless, in the judgment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant, prior to initiating an on-site investigation, the Department will await receipt of this information from the ICRC for 24 hours (or less if indicated) after receipt of the complaint. The Department may require a subsequent written report of the ICRC's findings, accompanied by pertinent records and documentation.

(3) On the basis of the information obtained during preliminary inquiry, including information provided by the hospital (including the hospital's ICRC, if any), information provided by the complainant, and all other information obtained, the Department will determine whether there is a need for an on-site investigation of the complaint. Whenever the Department determines that doubt remains that the recipient hospital or some other recipient is in compliance with this part or additional documentation is desired to substantiate a conclusion, the Department will initiate an on-site investigation or take some other appropriate action. Unless impracticable, prior to initiating an on-site investigation, the Department's medical consultant (referred to in paragraph 6) will contact the hospital's ICRC or appropriate medical personnel of the recipient hospital.

(4) In conducting on-site investigations, when a recipient hospital has an ICRC established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the investigation will begin with, or include at the earliest practicable time, a meeting with the ICRC or its designees. In all on-site investigations, the Department will make every effort to minimize any potential inconvenience or disruption, accommodate the schedules of health care professionals and avoid making medical records unavailable. The Department will also seek to coordinate its investigation with any related investigations by the state child protective services agency so as to minimize potential disruption.

(5) It is the policy of the Department to make no comment to the public or media regarding the substance of a pending preliminary inquiry or investigation.

(6) The Department will obtain the assistance of a qualified medical consultant to evaluate the medical information (including medical records) obtained in the course of a preliminary inquiry or investigation. The name, title and telephone number of the Department's medical consultant will be made available to the recipient hospital. The Department's medical consultant will, if appropriate, contact medical personnel of the recipient hospital in connection with the preliminary inquiry, investigation or medical consultant's evaluation. To the extent practicable, the medical consultant will be a specialist with respect to the condition of the infant who is the subject of the preliminary inquiry or investigation. The medical consultant may be an employee of the Department or another person who has agreed to serve, with or without compensation, in that capacity.

(7) The Department will advise the recipient hospital of its conclusions as soon as possible following the completion of a preliminary inquiry or investigation. Whenever final administrative findings following an investigation of a complaint of suspected life-threatening noncompliance cannot be made promptly, the Department will seek to notify the recipient and the complainant of the Department's decision on whether the matter will be immediately referred to the Department of Justice pursuant to 45 CFR 80.8.

(8) Except as necessary to determine or effect compliance, the Department will (i) in conducting preliminary inquiries and investigations, permit information provided by the recipient hospital to the Department to be furnished without names or other identifying information relating to the infant and the infant's family; and (ii) to the extent permitted by law, safeguard the confidentiality of information obtained.

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BOWEN, SECRETARY OF HEALTH AND HUMAN SERVICES *v.* AMERICAN HOSPITAL ASSOCIATION ET AL.

CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

No. 84–1529. Argued January 15, 1986—Decided June 9, 1986

Section 504 of the Rehabilitation Act of 1973 provides that "[n]o otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." In 1984, the Secretary of Health and Human Services (Secretary) promulgated regulations requiring: (1) health care providers receiving federal funds to post notices that because of § 504's prohibition against discrimination on the basis of handicap, health care should not be withheld from infants on the basis of their mental or physical impairments; (2) state child protective services agencies to establish procedures to prevent unlawful medical neglect of handicapped infants, and when considered necessary, in the judgment of the responsible official of the Department of Health and Human Services, to protect a handicapped infant's life or health; (3) immediate access to patient records; and (4) expedited compliance actions. In consolidated actions in Federal District Court, respondents sought to declare the regulations invalid and to enjoin their enforcement. The court granted the requested relief on the authority of *United States* v. *University Hospital*, 729 F. 2d 144 (CA2), and the Court of Appeals affirmed on the basis of that earlier decision.

Held: The judgment is affirmed.

794 F. 2d 676, affirmed.

JUSTICE STEVENS, joined by JUSTICE MARSHALL, JUSTICE BLACKMUN, and JUSTICE POWELL, concluded that the regulations in question are not authorized by § 504. Pp. 624–647.

(a) A hospital's withholding of treatment from a handicapped infant when no parental consent has been given cannot violate § 504, for without the parents' consent the infant is neither "otherwise qualified" for treatment nor has he been denied care "solely by reason of his handicap." There is nothing in the administrative record documenting the Secretary's belief that there exists "discriminatory withholding of medical care" in violation of § 504 which would justify federal regulation. None

Appendix H

Bowen v. American Hospital Association

of the examples cited by the Secretary as justification for the regulation suggest that the hospitals receiving federal funds, as opposed to parents, withheld medical care on the basis of handicap. Pp. 630–636.

(b) The complaint-handling process the Secretary would impose on unwilling state agencies is totally foreign to the authority to prevent discrimination conferred on him by § 504. While the Secretary can require state agencies to document their *own* compliance with § 504, nothing in § 504 authorizes him to commandeer state agencies to enforce compliance by *other* recipients of federal funds (in this instance, hospitals). Pp. 637–642.

(c) The Secretary's basis for federal intervention is perceived discrimination against handicapped infants in violation of § 504, and yet the Secretary has pointed to no evidence that such discrimination occurs. The administrative record does not contain the reasoning and evidence necessary to sustain federal intervention into a historically state-administered decisional process that appears—for lack of any contrary evidence—to be functioning in full compliance with § 504. Nothing in § 504 authorizes the Secretary to dispense with the law's focus on discrimination and instead to employ federal resources to save the lives of handicapped newborns, without regard to whether they are victims of discrimination by recipients of federal funds or not. Section 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children. The administrative record demonstrates that the Secretary has asserted the authority to conduct on-site investigations, to inspect hospital records, and to participate in the decisional process in emergency cases in which there was no colorable basis for believing that a violation of § 504 had occurred or was about to occur. These investigative actions are not authorized by § 504, and the regulations that purport to authorize a continuation of them are invalid. Pp. 642–647.

STEVENS, J., announced the judgment of the Court, and delivered an opinion in which MARSHALL, BLACKMUN, and POWELL, JJ., joined. BURGER, C. J., concurred in the judgment. WHITE, J., filed a dissenting opinion, in which BRENNAN, J., joined and in Parts I, II, IV, and V of which O'CONNOR, J., joined, *post*, p. 648. O'CONNOR, J., filed a dissenting opinion, *post*, p. 665. REHNQUIST, J., took no part in the consideration or decision of the case.

Deputy Assistant Attorney General Cooper argued the cause for petitioner. With him on the briefs were *Solicitor General Fried, Assistant Attorney General Reynolds, Dep-*

uty Solicitor General Wallace, *Edwin S. Kneedler*, *Brian K. Landsberg*, and *Mark L. Gross*.

Richard L. Epstein argued the cause for respondents American Hospital Association et al. With him on the brief were *Stuart M. Gerson*, *William G. Kopit*, *David H. Larry*, and *Robert W. McCann*. *Benjamin W. Heineman, Jr.*, argued the cause for respondents American Medical Association et al. With him on the brief were *Carter G. Phillips*, *Vincent F. Prada*, *Newton N. Minow*, *Jack R. Bierig*, *Ann E. Allen*, and *Joseph A. Keyes, Jr.**

JUSTICE STEVENS announced the judgment of the Court and delivered an opinion, in which JUSTICE MARSHALL, JUSTICE BLACKMUN, and JUSTICE POWELL join.

This case presents the question whether certain regulations governing the provision of health care to handicapped infants are authorized by § 504 of the Rehabilitation Act of 1973. That section provides, in part:

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*Briefs of *amici curiae* urging reversal were filed for the American Association on Mental Deficiency et al. by *James W. Ellis* and *Ruth A. Luckasson*; for the American Coalition of Citizens with Disabilities et al. by *Thomas K. Gilhool*, *Frank J. Laski*, *Michael Churchill*, and *Timothy M. Cook*; for the Associaion for Retarded Citizens of the United States et al. by *Martin H. Gerry*; for the Disability Rights Education & Defense Fund, Inc., et al. by *Barbara M. Milstein*; for the Rutherford Institute et al. by *W. Charles Bundren*, *Guy O. Farley, Jr.*, *James J. Knicely*, *John W. Whitehead*, *Thomas O. Kotouc*, *Wendell R. Bird*, and *William B. Hollberg*; for Carlton Johnson by *James Bopp, Jr.*, and *Thomas J. Marzen*; and for David G. McLone, M. D., et al. by *Dennis J. Horan*, *Victor G. Rosenblum*, *Edward R. Grant*, and *Maura K. Quinlan*.

Briefs of *amici curiae* urging affirmance were filed for the American Academy of Pediatrics et al. by *Stephan E. Lawton*, *Jack N. Goodman*, and *John A. Hodges*; for the State University of New York by *Robert Abrams*, Attorney General of New York, *Robert Hermann*, Solicitor General, *Frederick K. Mehlman*, *Stanley A. Camhi*, *Paul M. Glickman*, *Donna Miller*, *Martha O. Shoemaker*, and *Jane Levine*, Assistant Attorneys General, and *Sanford H. Levine*; and for George P. Smith II, *pro se*.

James Bopp, Jr., filed a brief for Senator Orrin G. Hatch et al. as *amici curiae*.

> "No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 87 Stat. 394, 29 U. S. C. § 794.[1]

I

The American Medical Association, the American Hospital Association, and several other respondents[2] challenge the validity of Final Rules promulgated on January 12, 1984, by the Secretary of the Department of Health and Human Services.[3] These Rules establish "Procedures relating to health care for handicapped infants," and in particular require the posting of informational notices, authorize expedited access to records and expedited compliance actions, and command state child protective services agencies to "prevent instances of unlawful medical neglect of handicapped infants." 45 CFR § 84.55 (1985).

Although the Final Rules comprise six parts, only the four mandatory components are challenged here.[4] Subsection (b) is entitled "Posting of informational notice" and requires every "recipient health care provider that provides health care services to infants in programs or activities receiving

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[1] "Handicapped individual" is defined in § 7(7)(B) of the Act, as amended, as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." 92 Stat. 2985, 29 U. S. C. § 706(7)(B).

[2] The respondents include the Hospital Association of New York State, the American College of Obstetricians and Gynecologists, the Association of American Medical Colleges, the American Academy of Family Physicians, and certain individual physicians.

[3] Margaret Heckler occupied the position of Secretary throughout the rulemaking period. On December 13, 1985, after certiorari had been granted, Dr. Otis Bowen assumed that position. Despite the fact that Dr. Bowen was not responsible for promulgation of the Final Rules, for the sake of continuity our references assume that he was. For ease of reference we refer to the Secretary, the Department, and HHS interchangeably.

[4] In subsection (a) the Department "encourages each recipient health care provider that provides health care services to infants" to establish an

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"Infant Care Review Committee (ICRC)" to assist in the development of treatment standards for handicapped infants and to provide assistance in making individual treatment decisions. 45 CFR § 84.55(a) (1985). In subsection (f), the Department describes its version of a model ICRC.

Subsection (f) also provides that "[t]he activities of the ICRC will be guided by . . . [t]he interpretative guidelines of the Department." 45 CFR § 84.55(f)(1)(ii)(A) (1985). These guidelines, which are "illustrative" and "do not independently establish rules of conduct," pt. 84, appendix C, ¶(a), set forth the Department's interpretation of § 504. Although they do not contain any definition of "discrimination," they do state that § 504 is not applicable to parents and that the regulation applies to only two categories of activities of hospitals: (1) refusals to provide treatment or nourishment to handicapped infants whose parents have consented to, or requested, such treatment; and (2) the failure or refusal to take action to override a parental decision to withhold consent for medically beneficial treatment or nourishment. With respect to the second category, the guidelines state that the hospital may not "solely on the basis of the infant's present or anticipated future mental or physical impairments, fail to follow applicable procedures on reporting such incidents to the child protective services agency or to seek judicial review." 45 CFR pt. 84, appendix C, ¶(a)(4) (1985).

With respect to the first category, the guidelines do not state that § 504 categorically prohibits a hospital from withholding requested treatment or nourishment "solely on the basis of present or anticipated physical or mental impairments of an infant." 45 CFR pt. 84, appendix C, ¶(a)(1). Rather, the substantive guidelines and two of the illustrative examples recognize that the etiology of and prognosis for particular handicapping conditions may justify "a refusal to treat solely on the basis of those handicapping conditions." ¶(a)(2) (§ 504 does not require "futile treatment"); ¶(a)(5)(iii) (§ 504 does not require treatment of anencephaly because it would "do no more than temporarily prolong the act of dying"); ¶(a)(iv) (same with severely premature and low birth weight infants). In general, the guidelines seem to make a hospital's liability under § 504 dependent on proof that (1) it refused to provide requested treatment or nourishment solely on the basis of an infant's handicapping condition, and (2) the treatment or nourishment would have been medically beneficial. See ¶¶(a)(1)–(3), (5).

The guidelines also describe how HHS will respond to "complaints of suspected life threatening noncompliance" with § 504 in this context, progress-

Federal financial assistance"—a group to which we refer generically as "hospitals"—to post an informational notice in one of two approved forms. 45 CFR § 84.55(b) (1985). Both forms include a statement that § 504 prohibits discrimination on the basis of handicap, and indicate that because of this prohibition "nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments." 45 CFR §§ 84.55(b)(3), (4) (1985). The notice's statement of the legal requirement does not distinguish between medical care for which parental consent has been obtained and that for which it has not. The notice must identify the telephone number of the appropriate child protective services agency and, in addition, a toll-free number for the Department that is available 24 hours a day. *Ibid.* Finally, the notice must state that the "identity of callers will be kept confidential" and that federal law prohibits retaliation "against any person who provides information about possible violations." *Ibid.*

Subsection (c), which contains the second mandatory requirement, sets forth "Responsibilities of recipient state child protective services agencies." Subsection (c) does not mention § 504 (or any other federal statute) and does not even use the word "discriminate." It requires every designated agency to establish and maintain procedures to ensure that

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ing from telephone inquiries to the hospital to obtain information about the condition of the infant, to requests for access to records, and finally to on-site investigations and litigation in appropriate cases. ¶ (b). The guidelines do not draw any distinction between cases in which parental consent has been withheld and those in which it has been given. Nor do they draw any distinction between cases in which hospitals have made a report of parental refusal to consent to treatment and those in which no report to a state agency has been made. They do announce that the "Department will also seek to coordinate its investigation with any related investigations by the state child protective services agency so as to minimize potential disruption," ¶ (b)(4), indicating that the Department's investigations may continue even in cases that have previously been referred to a state agency.

"the agency utilizes its full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants." 45 CFR § 84.55(c)(1). Mandated procedures must include (1) "[a] requirement that health care providers report on a timely basis . . . known or suspected instances of unlawful medical neglect of handicapped infants," § 84.55(c)(1)(i); (2) a method by which the state agency can receive timely reports of such cases, § 84.55(c)(1)(ii); (3) "immediate" review of those reports, including "on-site investigation," where appropriate, § 84.55(c)(1)(iii); (4) protection of "medically neglected handicapped infants" including, where appropriate, legal action to secure "timely court order[s] to compel the provision of necessary nourishment and medical treatment," § 84.55(c)(1)(iv); and (5) "[t]imely notification" to HHS of every report of "suspected unlawful medical neglect" of handicapped infants. The preamble to the Final Rules makes clear that this subsection applies "where a refusal to provide medically beneficial treatment is a result, not of decisions by a health care provider, but of decisions by parents." 49 Fed. Reg. 1627 (1984).

The two remaining mandatory regulations authorize "[e]xpedited access to records" and "[e]xpedited action to effect compliance." 45 CFR §§ 84.55(d), (e) (1985). Subsection (d) provides broadly for immediate access to patient records on a 24-hour basis, with or without parental consent, "when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual." § 84.55(d). Subsection (e) likewise dispenses with otherwise applicable requirements of notice to the hospital "when, in the judgment of the responsible Department official, immediate action to effect compliance is necessary to protect the life or health of a handicapped individual." § 84.55(e). The expedited compliance provision is intended to allow "the government [to] see[k] a temporary restraining order to sustain the life of a handicapped infant in imminent danger of death." 49 Fed. Reg. 1628 (1984). Like the provision affording expedited access to records, it applies without regard to whether parental consent to treatment has been withheld or whether the matter has already been referred to a state child protective services agency.

II

The Final Rules represent the Secretary's ultimate response to an April 9, 1982, incident in which the parents of a Bloomington, Indiana, infant with Down's syndrome and other handicaps refused consent to surgery to remove an esophageal obstruction that prevented oral feeding. On April 10, the hospital initiated judicial proceedings to override the parents' decision, but an Indiana trial court, after holding a hearing the same evening, denied the requested relief. On April 12 the court asked the local Child Protection Committee to review its decision. After conducting its own hearing, the Committee found no reason to disagree with the court's ruling.[5] The infant died six days after its birth.

Citing "heightened public concern" in the aftermath of the Bloomington Baby Doe incident, on May 18, 1982, the director of the Department's Office of Civil Rights, in response to a directive from the President, "remind[ed]" health care providers receiving federal financial assistance that newborn infants with handicaps such as Down's syndrome were protected by §504. 47 Fed. Reg. 26027 (1982).[6]

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[5] At the instance of the local prosecutor, the Indiana courts on April 13 held another hearing at which the court concluded that "Baby Doe" had not been neglected under Indiana's Child in Need of Services statute. Additional attempts to seek judicial intervention were rebuffed the same day. On the following day, the Indiana Court of Appeals denied a request for an immediate hearing. *In re Infant Doe*, No. GU 8204-004A (Monroe County Cir. Ct., Apr. 12, 1982). The Indiana Supreme Court, by a vote of 3 to 1, rejected a petition for a writ of mandamus. *State ex rel. Infant Doe* v. *Baker*, No. 482 S 140 (May 27, 1982). The infant died while a stay was being sought in this Court, and we subsequently denied certiorari. *Infant Doe* v. *Bloomington Hospital*, 464 U. S. 961 (1983).

This notice was followed, on March 7, 1983, by an "Interim Final Rule" contemplating a "vigorous federal role." 48 Fed. Reg. 9630. The Interim Rule required health care providers receiving federal financial assistance to post "in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery" a notice advising of the applicability of §504 and the availability of a telephone "hotline" to report suspected violations of the law to HHS. *Id.*, at 9631. Like the Final Rules, the Interim Rule also provided for expedited compliance actions and expedited access to records and facilities when, "in the judgment of the responsible Department official," immediate action or access was "necessary to protect the life or health of a handicapped individual." *Id.*, at 9632. The Interim Rule took effect on March 22.

On April 6, 1983, respondents American Hospital Association et al. filed a complaint in the Federal District Court for the Southern District of New York seeking a declaration that the Interim Final Rule was invalid and an injunction against its enforcement. Little more than a week later, on April 14, in a similar challenge brought by the American Academy of Pediatrics and other medical institutions, the Federal District Court for the District of Columbia declared the Interim Final Rule "arbitrary and capricious and promulgated in violation of the Administrative Procedure Act." *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 404 (1983). The District Judge in that case "conclude[d] that haste and inexperience ha[d] resulted in agency action based on inadequate consideration" of several relevant concerns and, in the alternative, found that the Secretary had improperly failed to solicit public comment before issuing the Rule. *Id.*, at 399–401.

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[6] The notice maintained that hospitals would violate §504 if they "allow[ed] [an] infant" to remain in their care after "the infant's parents or guardian [had withheld consent to] treatment or nourishment discriminatorily." 47 Fed. Reg. 26027 (1982). The Secretary no longer subscribes to this reading of the statute. See 49 Fed. Reg. 1631 (1984).

On July 5, 1983, the Department issued new "Proposed Rules" on which it invited comment. Like the Interim Final Rule, the Proposed Rules required hospitals to post informational notices in conspicuous places and authorized expedited access to records to be followed, if necessary, by expedited compliance action. 48 Fed. Reg. 30851. In a departure from the Interim Final Rule, however, the Proposed Rules required federally assisted state child protective services agencies to utilize their "full authority pursuant to State law to prevent instances of medical neglect of handicapped infants." *Ibid.* Mandated procedures mirrored those contained in the Final Rules described above. *Ibid.* The preamble and appendix to the Proposed Rules did not acknowledge that hospitals and physicians lack authority to perform treatment to which parents have not given their consent.[7]

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[7] In explaining the need for the Proposed Rules, the preamble, although mentioning "parental rights over their children," insisted that physicians' "acquiescence in nontreatment of Down's children is apparently *because of* the handicap," rather than, it must be supposed, lack of parental consent. 48 Fed. Reg. 30848 (1983).

The effect of parental nonconsent was not even mentioned in the appendix to the Proposed Rules. That section, which set forth the Department's view of "the manner in which Section 504 applies to the provision of health care services to handicapped infants," *id.*, at 30851, declared that § 504 mandated "the basic provision of nourishment, fluids, and routine nursing care." *Id.*, at 30852. The provision of sustenance, according to the Department, was "not an option for medical judgment." *Ibid.* Thus, "[e]ven if a handicapped infant faces imminent and unavoidable death, no health care provider should take upon itself to cause death by starvation or dehydration." *Ibid.*

In addition to its unqualified endorsement of nourishment as required by § 504, the appendix announced that "[a]ny decision not to correct intestinal atresia in a Down's Syndrome child, unless an additional complication medically warrants such decision, *must* be deemed a denial of services based on

After the period for notice and comment had passed, HHS, on December 30, 1983, promulgated the Final Rules and announced that they would take effect on February 13, 1984. On March 12 of that year respondents American Hospital Association et al. amended their complaint and respondents American Medical Association et al. filed suit to declare the new regulations invalid and to enjoin their enforcement. The actions were consolidated in the Federal District Court for the Southern District of New York, which awarded the requested relief on the authority of the decision of the United States Court of Appeals for the Second Circuit in *United States* v. *University Hospital*, 729 F. 2d 144 (1984). *American Hospital Assn.* v. *Heckler*, 585 F. Supp. 541 (1984); App. to Pet. for Cert. 50a. On appeal, the parties agreed that the reasoning of the Court of Appeals in *University Hospital*, if valid, required a judgment against the Government in this case.[8] In accordance with its earlier decision, the Court of Appeals summarily affirmed the District Court. 694 F. 2d 676 (1984). Since the judgment here thus rests entirely on the reasoning of *University Hospital*, it is appropriate to examine that case now.

III

On October 11, 1983, after the Department's Interim Final Rule had been declared invalid but before it had promulgated the Final Rules challenged here, a child with multiple congenital defects known as "Baby Jane Doe" was born in Long

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the handicap of Down's Syndrome. The same reasoning applies to a case of Down's Syndrome [infant] with esophogeal atresia, and the denial of surgery to correct atresia." *Ibid.* (emphasis added). The Department did not discuss the relevance of parental nonconsent to the hospital's treatment obligation under § 504, presumably because it was irrelevant given its understanding of the provision at that time.

[8] Indeed, although the Government took an appeal from the District Court's judgment, it filed a motion for summary disposition after the Court of Appeals denied its motion for initial consideration en banc. Its motion expressly acknowledged that an affirmance was compelled by the decision in *University Hospital*.

Island, New York, and was promptly transferred to University Hospital for corrective surgery. After consulting with physicians and other advisers, the parents decided to forgo corrective surgery that was likely to prolong the child's life, but would not improve many of her handicapping conditions.

On October 16, 1983, an unrelated attorney named Washburn filed suit in the New York Supreme Court, seeking the appointment of a guardian *ad litem* for the infant who would direct the hospital to perform the corrective surgery. The trial court granted that relief on October 20, but was reversed the following day by the Appellate Division which found that the "concededly concerned and loving parents" had "chosen one course of appropriate medical treatment over another" and made an informed decision that was "in the best interest of the infant." *Weber* v. *Stony Brook Hospital*, 95 App. Div. 2d 587, 589, 467 N. Y. S. 2d 685, 687 *(per curiam)*. On October 28, the New York Court of Appeals affirmed, but on the ground that the trial court should not have entertained a petition to initiate child neglect proceedings by a stranger who had not requested the aid of the responsible state agency. *Weber* v. *Stony Brook Hospital*, 60 N. Y. 2d 208, 211–213, 456 N. E. 2d 1186, 1187–1188 *(per curiam)*.

While the state proceedings were in progress, on October 19, HHS received a complaint from a "private citizen" that Baby Jane Doe was being discriminatorily denied medically indicated treatment. HHS promptly referred this complaint to the New York State Child Protective Service. (The agency investigated the charge of medical neglect and soon thereafter concluded that there was no cause for state intervention.) In the meantime, before the State Child Protective Service could act, HHS on October 22, 1983, made repeated requests of the hospital to make its records available for inspection in order to determine whether the hospital was in compliance with § 504. The hospital refused the requests and advised HHS that the parents had not consented to a release of the records.

Subsequently, on November 2, 1983, the Government filed suit in Federal District Court invoking its general authority to enforce §504 and 45 CFR §84.61 (1985), a regulation broadly authorizing access to information necessary to ascertain compliance. The District Court allowed the parents to intervene as defendants, expedited the proceeding, and ruled against the Government. It reasoned that the Government had no right of access to information because the record clearly established that the hospital had not violated the statute. *United States* v. *University Hospital, State Univ. of N. Y. at Stony Brook*, 575 F. Supp. 607, 614 (EDNY). Since the uncontradicted evidence established that the hospital "ha[d] at all times been willing to perform the surgical procedures in question, if only the parents . . . would consent," the hospital "failed to perform the surgical procedures in question, not because Baby Jane Doe [wa]s handicapped, but because her parents ha[d] refused to consent." *Ibid.*

The Court of Appeals affirmed. In an opinion handed down on February 23, 1984, six weeks after promulgation of the Final Rules, it agreed with the District Court that "an agency is not entitled to information sought in an investigation that 'overreaches the authority Congress has given.'" 729 F. 2d, at 150 (quoting *Oklahoma Press Publishing Co.* v. *Walling*, 327 U. S. 186, 217 (1946)). It further held that although Baby Jane Doe was a "handicapped individual," she was not "otherwise qualified" within the meaning of §504 because "where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to the need for services"; as a result "the 'otherwise qualified' criterion of section 504 cannot be meaningfully applied to a medical treatment decision." 729 F. 2d, at 156. For the same reason, the Court of Appeals rejected the Government's argument that Baby Jane Doe had been "subjected to discrimination" under §504: "Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory'." *Id.*, at 157. The difficulty of applying § 504 to individual medical treatment decisions confirmed the Court of Appeals in its view that "[C]ongress never contemplated that section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants when the statute was enacted in 1973, when it was amended in 1974, or at any subsequent time." *Id.*, at 161. It therefore rejected "the far-reaching position advanced by the government in this case" and concluded that until Congress had spoken, "it would be an unwarranted exercise of judicial power to approve the type of investigation that ha[d] precipitated this lawsuit." *Ibid.*

Judge Winter dissented. He pointed out that § 504 was patterned after § 601 of the Civil Rights Act of 1964, which prohibits discrimination on the basis of race in federally funded programs, and asserted that a refusal to provide medical treatment because of a person's handicapping condition is as clearly covered by § 504 as a refusal based on a person's race is covered by § 601:

> "A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent." *Id.*, at 162.

The Government did not file a certiorari petition in *University Hospital*. It did, however, seek review of the judgment in this case. We granted certiorari, 472 U. S. 1016 (1985), and we now affirm.

IV

The Solicitor General is correct that "handicapped individual" as used in § 504 includes an infant who is born with a congenital defect. If such an infant is "otherwise qualified" for benefits under a program or activity receiving federal financial assistance, § 504 protects him from discrimination "solely by reason of his handicap."[9] It follows, under our decision in *Alexander* v. *Choate*, 469 U. S. 287, 301 (1985), that handicapped infants are entitled to "meaningful access" to medical services provided by hospitals, and that a hospital rule or state policy denying or limiting such access would be subject to challenge under § 504.

However, no such rule or policy is challenged, or indeed has been identified, in this case. Nor does this case, in contrast to the *University Hospital* litigation, involve a claim that any specific individual treatment decision violates § 504. This suit is not an enforcement action, and as a consequence it is not necessary to determine whether § 504 ever applies to individual medical treatment decisions involving handicapped infants. Respondents brought this litigation to challenge the four mandatory components of the Final Rules on their face,[10] and the Court of Appeals' judgment which we review merely affirmed the judgment of the District Court which "declared invalid and enjoined enforcement of [the final] regulations, purportedly promulgated pursuant to section 504 of the Rehabilitation Act of 1973, 29 U. S. C. § 794 (1982)." App. to Pet. for Cert. 2a.[11] The specific question presented by this case, then, is whether the four mandatory provisions of the Final Rules are authorized by § 504.

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[9] As the case comes to us, we have no reason to review the Court of Appeals' assumption that the provision of health care to infants in hospitals receiving Medicare or Medicaid payments is a part of a "program or activity receiving Federal financial assistance." See *Consolidated Rail Corp.* v. *Darrone*, 465 U. S. 624, 635–636 (1984).

[10] See, *e. g.*, Brief in Opposition for Respondents American Medical Assn. et al. 7–8, n. 8; Record, Doc. No. 4, Memorandum of Points and Authorities in Support of Plaintiffs' Motion for Preliminary Injunction 12 ("The Final Regulation which is challenged in this action contains four mandatory provisions" (citations omitted)); *id.*, at 28 ("After *University Hospital* . . . must fall all of the mandatory obligations imposed by the Final Regulation"). Cf. App. 138–140 (complaint of American Medical Association et al.).

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[11] It is true that the District Court, in addition to declaring "[t]he Final Regulation . . . invalid and unlawful as exceeding" § 504 and enjoining petitioner from "any further implementation of the Final Regulation," also declared invalid and enjoined "[a]ny other actions" of the Secretary "to regulate treatment involving impaired newborn infants taken under authority of Section 504, including currently pending investigation and other enforcement actions." App. to Pet. for Cert. 51a. This language must, however, be given a limited construction. The complaints in this case did not challenge the Department's authority to regulate all treatment decisions, but more precisely the mandatory provisions of the Final Rules and enforcement activity along those lines but undertaken pursuant to the Department's "general authority" to enforce § 504, as occurred in the *University Hospital* litigation and in 41 of the 49 full-scale investigations conducted by the Secretary up to that point in time. See App. 138–139 (complaint of American Medical Association et al.); *id.*, at 145 (same); *id.*, at 159 (complaint of American Hospital Association et al.). See also Record, Doc. No. 4, Memorandum of Points and Authorities in Support of Plaintiffs' Motion for Preliminary Injunction 10–11. From these pleadings, the Court of Appeals apparently interpreted the District Court's use of the word "any" to forbid "[a]ny other actions" resembling the "currently pending investigation and other enforcement actions" specified in the injunction, App. to Pet. for Cert. 51a, rather than all possible regulatory and investigative activity that might involve the provision of health care to handicapped infants. Thus, as will become clear from our analysis of the Final Rules below, the injunction forbids continuation or initiation of regulatory and investigative activity directed at instances in which parents have refused consent to treatment and, if the Secretary were to undertake such action, efforts to seek compliance with affirmative requirements imposed on state child protective services agencies. "Because of the rightly serious view courts have traditionally taken of violations of injunctive orders, and because of the severity of punishment which may be imposed for such violation," *Pasadena City Bd. of Education* v. *Spangler*, 427 U. S. 424, 439 (1976); see *Longshoremen* v. *Marine Trade Assn.*, 389 U. S. 64, 76 (1967); *Gunn* v. *University Committee*, 399 U. S. 383, 389 (1970), the Court of Appeals properly construed the District Court's judgment as pertaining to the regulations challenged in this litigation (and enforcement activity independent of the Final Rules but paralleling the procedures set forth therein). Cf. *Schmidt* v. *Lessard*, 414 U. S. 473, 477 (1974) *(per curiam)*

V

It is an axiom of administrative law that an agency's explanation of the basis for its decision must include "a 'rational connnection between the facts found and the choice made.'" *Motor Vehicle Mfrs. Assn.* v. *State Farm Mut. Automobile Ins. Co.*, 463 U. S. 29, 43 (1983) (quoting *Burlington Truck Lines, Inc.* v. *United States*, 371 U. S. 156, 168 (1962)).[11] Agency deference has not come so far that we will uphold regulations whenever it is possible to "conceive a basis" for administrative action. To the contrary, the "presumption of

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(noting desirability of precise construction of injunction orders to facilitate appellate review). It is, of course, the Court of Appeals' judgment that we are called on to review, not the District Court's. See *Union Pacific R. Co.* v. *Chicago, R. I. & P. R. Co.*, 163 U. S. 564, 593 (1896). Cf. *Davis* v. *Packard*, 6 Pet. 41, 49 (1832). Accordingly, we give great weight to the Court of Appeals' construction of the judgment it affirmed. Cf. *United States* v. *Colgate & Co.*, 250 U. S. 300, 301–302 (1919). For purposes of comparison, the dissent's expansive reading of the judgment is supported neither by the Court of Appeals nor by the parties. See Brief for Respondents American Medical Assn. et al. 14, 48, n. 60. Cf. Brief for Respondents American Hospital Assn. et al. 4 (quoting final judgment of the District Court). In view of the fact that we affirm this judgment on reasoning narrower than that employed by the lower courts, it bears repetition that this Court "reviews judgments, not opinions." *Chevron U. S. A. Inc.* v. *Natural Resources Defense Council, Inc.*, 467 U. S. 837, 842 (1984). See, *e. g.*, *Black* v. *Cutter Laboratories*, 351 U. S. 292, 297 (1956); *J. E. Riley Investment Co.* v. *Commissioner*, 311 U. S. 55, 59 (1940); *Williams* v. *Norris*, 12 Wheat. 117, 120 (1827); *McClung* v. *Silliman*, 6 Wheat. 598, 603 (1821).

[11] See *Baltimore Gas & Electric Co.* v. *Natural Resources Defense Council, Inc.*, 462 U. S. 87, 105–106 (1983); *Bowman Transportation, Inc.* v. *Arkansas-Best Freight System, Inc.*, 419 U. S. 281, 285–286 (1974); *FTC* v. *Sperry & Hutchinson Co.*, 405 U. S. 233, 249 (1972); *FPC* v. *United Gas Pipe Line Co.*, 393 U. S. 71, 72–73 (1968) *(per curiam)*; *Siegel Co.* v. *FTC*, 327 U. S. 608, 613 (1946).

regularity afforded an agency in fulfilling its statutory mandate," is not equivalent to "the minimum rationality a statute must bear in order to withstand analysis under the Due Process Clause." *Motor Vehicle Mfrs. Assn.* v. *State Farm Mut. Automobile Ins. Co.*, 463 U. S., at 43, n. 9. Thus, the mere fact that there is "some rational basis within the knowledge and experience of the [regulators]," *United States* v. *Carolene Products Co.*, 304 U. S. 144, 152 (1938) (footnote omitted), under which they "might have concluded" that the regulation was necessary to discharge their statutorily authorized mission, *Williamson* v. *Lee Optical Co.*, 348 U. S. 483, 487 (1955), will not suffice to validate agency decisionmaking. See *Industrial Union Dept.* v. *American Petroleum Inst.*, 448 U. S. 607, 639–659 (1980) (opinion of STEVENS, J.); *Burlington Truck Lines, Inc.* v. *United States*, 371 U. S. 156, 169 (1962). Our recognition of Congress' need to vest administrative agencies with ample power to assist in the difficult task of governing a vast and complex industrial Nation carries with it the correlative responsibility of the agency to explain the rationale and factual basis for its decision, even though we show respect for the agency's judgment in both.

Before examining the Secretary's reasons for issuing the Final Rules, it is essential to understand the pre-existing state-law framework governing the provision of medical care to handicapped infants. In broad outline, state law vests decisional responsibility in the parents, in the first instance, subject to review in exceptional cases by the State acting as *parens patriae*.[13] Prior to the regulatory activity culminat-

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[13] The basic pattern of decisionmaking is well summarized in the 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

"The paucity of directly relevant cases makes characterization of the law in this area somewhat problematic, but certain points stand out. First, there is a presumption, strong but rebuttable, that parents are the approing in the Final Rules, the Federal Government was not a participant in the process of making treatment decisions for newborn infants. We presume that this general framework was familiar to Congress when it enacted § 504. See *Cannon* v. *University of Chicago*, 441 U. S. 677, 696–697 (1979). It therefore provides an appropriate background for evaluating the Secretary's action in this case.

The Secretary has identified two possible categories of violations of § 504 as justifications for federal oversight of handicapped infant care. First, he contends that a hospital's refusal to furnish a handicapped infant with medically beneficial treatment "solely by reason of his handicap" constitutes unlawful discrimination. Second, he maintains that a hospital's failure to report cases of suspected medical neglect to a

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priate decisionmakers for their infants. Traditional law concerning the family, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents. Second, as persons unable to protect themselves, infants fall under the *parens patriae* power of the state. In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children but may also supervene parental decisions before they become operative to ensure that the choices made are not so detrimental to a child's interests as to amount to neglect and abuse.

". . . [A]s long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court and even less frequently supervened. The courts have exercised their authority to appoint a guardian for a child when the parents are not capable of participating in the decisionmaking or when they have made decisions that evidence substantial lack of concern for the child's interests. Although societal involvement usually occurs under the auspices of governmental instrumentalities—such as child welfare agencies and courts—the American legal system ordinarily relies upon the private initiative of individuals, rather than continuing governmental supervision, to bring the matter to the attention of legal authorities." Report, at 212–214 (footnotes omitted).

This summary accords with the Secretary's understanding of the state-law framework, at least in other contexts. See 50 Fed. Reg. 14880 (1985) (final rule implementing Child Abuse Amendments of 1984) ("The decision to provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian").

state child protective services agency may also violate the statute. We separately consider these two possible bases for the Final Rules.[14]

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[14] Rather than address these issues, the dissent would remand to the Court of Appeals. See *post*, at 656. In light of its willingness to address the broader hypothetical question whether § 504 ever authorizes regulation of medical treatment decisions—"even if the judgment below were limited to invalidation of these regulations," *post*, at 650, n. 4—it comes as something of a surprise to read the references to the Solicitor General's argument that "this claim in its current form is not properly in the case," *post*, at 657, n. 9. The procedural objections are plainly without substance. Respondents AMA et al. raised the lack of factual support in their brief in opposition to the petition for certiorari. See Brief in Opposition for Respondents American Medical Association et al. 20 ("First, the fundamental problem with the Secretary's position is that it is based on a situation that has not occurred—and will not occur—in real life. . . . Not surprisingly, the Secretary cites no case where [his hypothetical problem] has occurred"); *id.*, at 20–21; *id.*, at 26 ("B. The Secretary Has Shown No Problem With the Historic State Law Framework That Warrants Direct Federal Investigation and Regulation"); *id.*, at 26–29. The Solicitor General, although responding that such evidence exists, see Reply Memorandum for Petitioner 9, did not raise a procedural bar. As a result, the objection is waived. See *Oklahoma City* v. *Tuttle*, 471 U. S. 808, 815–816 (1985). Although further discussion of this objection is therefore unnecessary, the dissent is also wrong in suggesting that respondents' complaints did not raise "the lack of a factual basis involving situations in which parents *have* consented to treatment." *Post*, at 657, n. 9. In fact, the complaint of respondents AMA et al. alleged "COUNT II: Violation of the Administrative Procedure Act," App. 146, and incorporated by reference the allegation that "None of the mandatory provisions of the Final Regulation have a basis in fact or are designed to meet a documented problem," *id.*, at 140. Accord, *id.*, at 158 (complaint of respondents AHA et al.). The fact that our decision rests on grounds narrower than that relied on by the lower courts is surely not an infirmity. We can only add that the lack of factual support for these regulations was fully briefed in this Court, see especially Brief for Respondents American Medical Assn. et al. 39–41; Brief for Respondents American Hospital Assn. et al. 48–49, and the fact that the Solicitor General responds with so little, so late bespeaks the absence of evidentiary support for the regulations, not an inadequate opportunity to direct us to it.

The Solicitor General also contends, for the first time in his reply brief on the merits, see Reply Brief for Petitioner 16, n. 6, that the Final Rules are

VI

In the immediate aftermath of the Bloomington Baby Doe incident, the Secretary apparently proceeded on the assumption that a hospital's statutory duty to provide treatment to handicapped infants was unaffected by the absence of parental consent. See *supra*, at 617–619. He has since abandoned that view. Thus, the preamble to the Final Rules correctly states that when "a non-treatment decision, no matter how discriminatory, is made by parents, rather than by the hospital, section 504 does not mandate that the hospital unilaterally overrule the parental decision and provide treatment notwithstanding the lack of consent." 49 Fed. Reg. 1631 (1984). A hospital's withholding of treatment when no parental consent has been given cannot violate § 504, for without the consent of the parents or a surrogate decisionmaker the infant is neither "otherwise qualified" for treatment nor has he been denied care "solely by reason of his handicap."[11] Indeed, it would almost certainly be a tort as a matter of state law to operate on an infant without parental consent. This analysis makes clear that the Government's heavy reliance on the analogy to race-based refusals which violate § 601

"interpretative guidelines" which "merely explained the Secretary's construction of Section 504 in this setting," *ibid.* This assertion was rejected the only occasion on which it was tendered, see *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 401 (DC 1983), is belied by the Secretary's own decision to provide notice and request comment on the regulations, cf. 5 U. S. C. § 553(b), and is patently without merit. To its credit, the dissent does not ultimately rely on either of these arguments. See *post*, at 657, n. 9.

[11] Just as "[t]he failure of the hospital to itself provide the treatment" because of the unavailability of medical equipment or expertise would not be "on the basis of the handicap" but "on the fact that the hospital is incapable of providing the treatment," according to the Secretary's regulations, 49 Fed. Reg. 1637 (1984), it is equally clear that a refusal to provide care because of the absence of parental consent would not be "solely by reason of [the infant's] handicap."

of the Civil Rights Act is misplaced. If, pursuant to its normal practice, a hospital refused to operate on a black child whose parents had withheld their consent to treatment, the hospital's refusal would not be based on the race of the child even if it were assumed that the parents based *their decision* entirely on a mistaken assumption that the race of the child made the operation inappropriate.

Now that the Secretary has acknowledged that a hospital has no statutory treatment obligation in the absence of parental consent, it has become clear that the Final Rules are not needed to prevent hospitals from denying treatment to handicapped infants. The Solicitor General concedes that the administrative record contains no evidence that hospitals have ever refused treatment authorized either by the infant's parents or by a court order. Tr. of Oral Arg. 8. Even the Secretary never seriously maintained that posted notices, "hotlines," and emergency on-site investigations were necessary to process complaints against hospitals that might refuse treatment requested by parents. The parental interest in calling such a refusal to the attention of the appropriate authorities adequately vindicates the interest in enforcement of § 504 in such cases, just as that interest obviates the need for a special regulation to deal with refusals to provide treatment on the basis of race which may violate § 601 of the Civil Rights Act.

The Secretary's belated recognition of the effect of parental nonconsent is important, because the supposed need for federal monitoring of hospitals' treatment decisions rests *entirely* on instances in which parents have refused their consent. Thus, in the Bloomington, Indiana, case that precipitated the Secretary's enforcement efforts in this area,[16] as

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[16] The Secretary's summary of this case makes it clear that the hospital's failure to perform surgery was based on the parents' refusal of consent:

"*Bloomington, Indiana.* Investigation into April 1982, death of infant with Down's syndrome and esophageal atresia from whom surgery was well as in the *University Hospital* case that provided the basis for the summary affirmance in the case now before us,[17] the hospital's failure to perform the treatment at issue rested on the lack of parental consent. The Secretary's own summaries of these cases establish beyond doubt that the respective hospitals did not withhold medical care on the basis of handicap and therefore did not violate § 504; as a result, they provide no support for his claim that federal regulation is needed in order to forestall comparable cases in the future.

The Secretary's initial failure to recognize that withholding of consent by *parents* does not equate with discriminatory denial of treatment by *hospitals* likewise undermines the Secretary's findings in the preamble to his proposed rulemaking. In that statement, the Secretary cited four sources in support of the claim that "Section 504 [is] not being uniformly followed." 48 Fed. Reg. 30847 (1983). None of the cited examples, however, suggests that recipients of federal financial assistance, as opposed to parents, had withheld medical care on the basis of handicap.[18]

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withheld *on the instructions of the parents.*" *Id.*, at 1646 (emphasis added).

As recounted earlier, the hospital initiated judicial review to override the parents' decision, but its efforts proved unavailing. The Solicitor General now acknowledges that there was no basis for finding a violation of § 504 in this case. See Tr. of Oral Arg. 12.

[17] Notwithstanding that the Secretary's summary of this case demonstrates both that treatment was withheld because of refusal of parental consent and that state-court proceedings to override the parents' decision had been instituted before the Department intervened, the Department proceeded with its own investigation anyway:

"*Long Island, New York.* October 19, 1983, complaint, based on newspaper article, that infant with spina bifida not receiving surgery *due to refusal of parents to consent; legal proceedings ha[d] been initiated in State court.* Inquiry initiated October 19. On October 27, HHS asked Department of Justice to commence legal action to overcome refusal of hospital to permit review of pertinent records." 49 Fed. Reg. 1649 (1984) (emphasis added).

[18] The Secretary first cited a 1973 survey by Raymond Duff and A. G. M. Campbell calculating that 14% of deaths in the special nursery of the Yale-

Notwithstanding the ostensible recognition in the preamble of the effect of parental nonconsent on a hospital's obligation to provide care, in promulgating the Final Rules the Secretary persisted in relying on instances in which parents had refused consent to support his claim that, regardless of its "magnitude," there is sufficient evidence of "illegality" to justify "establishing basic mechanisms to allow for effective enforcement of a clearly applicable statute." 49 Fed. Reg. 1645 (1984). We have already discussed one source of this evidence—"the several specific cases cited in the preamble to the proposed rule." *Ibid.* Contrary to the Secretary's belief, these cases do *not* "support the proposition that handicapped infants may be subjected to unlawful discrimination." *Ibid.* In addition to the evidence relied on in prior notices, the Secretary included a summary of the 49 "Infant Doe

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New Haven hospital "were related to withholding treatment." 48 Fed. Reg. 30847 (1983). The Secretary's solitary quotation from this study, accurately illustrating the locus of the treatment decisions reviewed by the authors, involved refusal of parental consent:

"'An infant with Down's syndrome and intestinal atresia, like the much publicized one at Johns Hopkins Hospital, was not treated *because his parents thought the surgery was wrong for their baby and themselves.* He died several days after birth.'" *Ibid.* (emphasis added) (quoting Duff & Campbell, Moral and Ethical Dilemmas in the Special-Care Nursery, 289 New Eng. J. Med. 890, 891 (1973)).

The Secretary next referred to an incident at Johns Hopkins Hospital which, as the above quotation intimates, also concerned parental refusal of consent. Then followed brief mention of the "Bloomington Baby Doe" incident, in which the parents, as the Secretary now admits, refused consent to treatment despite the hospital's insistence that it be provided. The Secretary's fourth and final example involved "a 1979 death of an infant with Down's syndrome and an intestinal obstruction at the Kapiolani-Children's Medical Center in Honolulu, Hawaii," 48 Fed. Reg. 30847 (1983), which again appears to have resulted from "a lack of parental consent," *id.*, at 30848.

Generalizing from these examples, the Secretary reported the results of a survey of physician attitudes. He faulted "[t]heir acquiescence in nontreatment of Down's children" which he surmised was "apparently *because of* the handicap represented by Down's syndrome." *Ibid.* See n. 22, *infra.*

cases" that the Department had processed before December 1, 1983.[19] Curiously, however, by the Secretary's own admission *none* of the 49 cases had "resulted in a finding of discriminatory withholding of medical care." *Id.*, at 1649. In fact, in the entire list of 49 cases there is no finding that a hospital failed or refused to provide treatment to a handicapped infant for which parental consent had been given.[20]

Notwithstanding this concession, the Secretary "believes three of these cases demonstrate the utility of the procedural mechanisms called for in the final rules." *Ibid.* Accord, *ibid.* ("[T]hese cases provide additional documentation of the need for governmental involvement and the appropriateness of the procedures established by the final rules"). However, these three cases, which supposedly provide the strongest support for federal intervention, fail to disclose any discrimination against handicapped newborns in violation of § 504. For example, in Robinson, Illinois, the Department conducted an on-site investigation when it learned that the "hospital *(at the parents' request)* failed to perform necessary surgery." *Id.*, at 1646 (emphasis added). After "[t]he parents refused consent for surgery," "the hospital referred the matter to state authorities, who accepted custody of the infant and arranged for surgery and adoption," all "in compliance with section 504." *Ibid.* The Secretary concluded that "the involvement of the state child protective services agency," at the behest of the hospital, "was the most important element in bringing about corrective surgery for the infant. . . . Had there been no *governmental* involvement in the case, the outcome might have been much less favorable." *Id.*, at 1649 (emphasis added).[21]

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[19] The Secretary also reprinted selected quotations from various commenters reporting the existence of "discriminatory" decisions denying sustenance and care to handicapped infants. None of these comments disclosed whether those "discriminatory" decisions were made by parents or by hospitals.

[20] The Secretary's repeated inability to identify a single treatment decision in violation of § 504 lends an aura of unreality to JUSTICE WHITE's criticism of the Court of Appeals' decision in *University Hospital*. In explaining why he believes "the stated basis for the Court of Appeals' holding in *University Hospital* was incorrect," *post*, at 656; see *post*, at 655, n. 8, JUSTICE WHITE completely ignores the fact that the case involved a specific treatment decision made by parents. Since JUSTICE WHITE elsewhere agrees that parental decisions are not covered by § 504, *post*, at 657, n. 10, and that the infant involved in the *University Hospital* case was therefore not "otherwise qualified" for treatment, *post*, at 654, n. 7, he implicitly acknowledges that the *judgment* in *University Hospital* is correct; only by ignoring the actual facts of that case—as well as the actual facts of the 49 cases that were investigated by the Secretary—and speculating about nonexistent hypothetical cases in which a hospital might refuse to provide treatment requested by parents, does the dissent offer any basis for questioning the decision in *University Hospital*.

Indeed, even the dissent's criticism of the *reasoning* of the Court of Appeals' decision is based on a hypothetical situation that the Court of Appeals did not address. That court was concerned with the treatment of cases in which "the handicapping condition *is related* to the condition(s) to be treated," 729 F. 2d, at 157 (emphasis added); see *id.*, at 147, whereas JUSTICE WHITE has carefully limited his hypothetical discussion to cases in which "the treatment *is completely unrelated* to the baby's handicapping condition." *Post*, at 655 (emphasis added). Thus, like bishops of opposite colors, the opinions of JUSTICE WHITE and the Court of Appeals do not even touch one another.

The Secretary's second example illustrates with even greater force the effective and nondiscriminatory functioning of state mechanisms and the consequent lack of support for federal intervention. In Daytona Beach, Florida, the Department's hotline received a complaint of medical neglect of a handicapped infant; immediate contact with the hospital and state agency revealed that "the parents did not consent to surgery" for the infant. *Id.*, at 1648. Notwithstanding this information, which was confirmed by both the hospital and the state agency, and despite the fact that the state agency had "obtained a court order to provide surgery" the day *before* HHS was notified, the Department conducted an on-site investigation. *Ibid.* In the third case, in Colorado Springs, Colorado, the Department intervened so soon after birth that "the decisionmaking process was in progress at the time the OCR [Office of Civil Rights] inquiry began," and "it is impossible to say the surgery would not have been provided without this involvement." *Id.*, at 1649. "However," the Secretary added, "the involvement of OCR and the OCR medical consultant was cooperatively received by the hospital and apparently constructive." *Ibid.*

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[21] The preamble repeatedly makes the assumption that evidence showing the need for *governmental* involvement provides a basis for *federal* involvement. See, *e. g.*, 49 Fed. Reg. 1649 (1984).

In sum, there is nothing in the administrative record to justify the Secretary's belief that "discriminatory withholding of medical care" in violation of § 504 provides any support for federal regulation: In two of the cases (Robinson, Illinois, and Daytona Beach, Florida), the hospital's refusal was based on the absence of parental consent, but the parents' decision was overridden by state authorities and the operation was performed; in the third case (Colorado Springs, Colorado) it is not clear whether the parents would have given their consent or not, but the corrective surgery was in fact performed.[22]

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[22] JUSTICE WHITE's dissent suggests that regulation of health care providers can be justified on a theory the Secretary did not advance—a supposed need to curtail discriminatory advice by biased physicians. See *post*, at 658–661. After observing that at least some handicapped infants have not been treated, the dissent identifies physician attitudes as a likely explanation and concludes that mandated informational notices were presumably designed to "foste[r] an awareness by health care professionals of their responsibility not to act in a discriminatory manner with respect to medical treatment decisions for handicapped infants." *Post*, at 660.

The dissent's theory finds no support in the text of the regulation, the reasoning of the Secretary, or the briefs filed on his behalf in this Court. The regulations in general—and the informational notices in particular—do not purport to place any constraints on the advice that physicians may give their patients. Moreover, since it is now clear that parental decisionmaking is not covered by § 504, *supra*, at 630–631, the dissent's theory rests on the unstated premise that the statute may prevent the giving of advice to do something which § 504 does not itself prohibit. It is hardly obvious that the Rehabilitation Act of 1973 prohibits physicians from "aiding and abet-

VII

As a backstop to his manifestly incorrect perception that withholding of treatment in accordance with parental instructions necessitates federal regulation, the Secretary contends that a hospital's failure to report parents' refusals to consent to treatment violates § 504, and that past breaches of this kind justify federal oversight.

By itself, § 504 imposes no duty to report instances of medical neglect—that undertaking derives from state-law reporting obligations or a hospital's own voluntary practice. Although a hospital's selective refusal to report medical neglect of handicapped infants might violate § 504,[23] the Secretary

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ting" a parental decision which parents admittedly have a right to make. And if Congress did intend this counterintuitive result, one might expect an explanation from the Secretary as to how the hotlines and emergency on-site inspections contemplated by the Final Rules square with the constitutional doctrines on regulation, direct or indirect, of speech in general and of decisionmaking by health professionals in particular.

In reality, the Secretary neither found nor implied that physicians' predispositions against treating handicapped infants had resulted in parental refusals to consent to treatment. Indeed, he principally relied on attitudinal surveys for the converse proposition that regulation is necessary because parents refuse consent to treatment and physicians will "acquiesce in parental refus[als] to treat." 48 Fed. Reg. 30848 (1983). To the extent *any* theory may be discerned in the Secretary's two-column summary of physician surveys, it is that doctors would not *correct* "bad" parental decisions, not that they were responsible for helping them to make such choices in the first place. Moreover, even if the Secretary had relied on this evidence to insinuate that doctors imposed their own value judgments on parents by lobbying them to refuse consent, he never explains that the parental decisionmaking process is one in which doctors exercise the decisive influence needed to force such results. Compare *ibid.*, with *post*, at 658–659. The Secretary, in short, has not even adumbrated a theory of "discrimination" remotely resembling the one invented by the dissent, and therefore has not made the essential connection between the evidence of physician attitudes and the regulatory choice made here.

[23] Of course, § 504 would be violated only if the hospital failed to report medical neglect of a handicapped infant when it would report such neglect of a similarly situated nonhandicapped infant. Because respondents have

has failed to point to any specific evidence that this has occurred. The 49 actual investigations summarized in the preamble to the Final Rules do not reveal *any* case in which a hospital either failed, or was accused of failing, to make an appropriate report to a state agency.[24] Nor can we accept the Solicitor General's invitation to infer discriminatory nonreporting from the studies cited in the Secretary's proposed rulemaking. Even assuming that cases in which parents have withheld consent to treatment for handicapped infants have gone unreported, that fact alone would not prove

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challenged the Secretary's regulations on their face, we have no occasion to address the question whether infants with birth defects are similarly situated with infants in need of blood transfusions (the paradigm case in which hospitals have reported or have sought to override parental decisions, according to the Solicitor General, Brief for Petitioner 28, and n. 16), or whether a hospital could legitimately distinguish between the two situations on the basis of the different risks and benefits inhering in certain operations to correct birth defects, on the one hand, and blood transfusions, on the other hand.

[24] To the contrary, the Secretary's case summaries reveal numerous instances in which hospitals have voluntarily reported instances of suspected medical neglect and have even initiated legal proceedings themselves. In the Bloomington, Indiana, case which prompted these regulations, and in the *University Hospital* case which supported the summary affirmance now before us, the parents' decision was the subject of judicial review in the state courts. In the Robinson, Illinois, case on which the Secretary relies as one of three examples illustrating the need for federal regulation, the hospital reported the parents' refusal to consent to state authorities who arranged for surgery and adoption. 49 Fed. Reg. 1646 (1984). Most dramatically, in the Daytona Beach, Florida, case HHS received its hotline complaint the day *after* the state agency had already obtained a court order overriding the parents' refusal to consent to surgery. *Id.*, at 1648. Notwithstanding the Department's "immediate contact" with the hospital *and the state agency*—which surely must have made it clear that the case had already been reported to that agency and that there was no colorable basis for suspecting a violation of § 504—the Department conducted an on-site investigation. *Ibid.* In the third case on which the Secretary placed special emphasis, the Department intervened before the parents had decided whether to authorize treatment or not, so that no reporting obligation could have been triggered. *Ibid.*

that the hospitals involved had discriminated on the basis of handicap rather than simply failed entirely to discharge their state-law reporting obligations, if any, a matter which lies wholly outside the nondiscrimination mandate of § 504.

The particular reporting mechanism chosen by the Secretary—indeed the entire regulatory framework imposed on state child protective services agencies—departs from the nondiscrimination mandate of § 504 in a more fundamental way. The mandatory provisions of the Final Rules omit any direct requirement that hospitals make reports when parents refuse consent to recommended procedures.[25] Instead, the Final Rules command *state agencies* to require such reports, regardless of the state agencies' own reporting requirements (or lack thereof). 45 CFR § 84.55(c)(1)(i) (1985). Far from merely preventing state agencies from remaining calculatedly indifferent to handicapped infants while they tend to the needs of the similarly situated nonhandicapped, the Final Rules command state agencies to utilize their "full authority" to "prevent instances of unlawful medical neglect of handicapped infants." § 84.55(c)(1). The Rules effectively make medical neglect of handicapped newborns a state investigative priority, possibly forcing state agencies to shift scarce resources away from other enforcement activities—perhaps even from programs designed to protect handicapped children outside hospitals. The Rules also order state agencies to "immediate[ly]" review reports from hospitals, § 84.55(c)(1)(iii), to conduct "on-site investigation[s]," *ibid.*, and to take legal action "to compel the provision of necessary nourishment and medical treatment,"

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[25] The interpretative guidelines appended to the Final Rules do impose on hospitals and other health care providers the duty not to discriminate against handicapped infants in reporting instances of parental neglect. We do not address the question whether reporting, either as a hospital practice or as a requirement of state law, constitutes a "program or activity receiving Federal financial assistance" under § 504. See *Consolidated Rail Corp.* v. *Darrone*, 465 U. S., at 635–636. Cf. *Grove City College* v. *Bell*, 465 U. S. 555, 570–574 (1984).

§ 84.55(c)(1)(iv)—all without any regard to the procedures followed by state agencies in handling complaints filed on behalf of nonhandicapped infants. These operating procedures were imposed over the objection of several state child protective services agencies that the requirement that they turn over reports to HHS "conflicts with the confidentiality requirements of state child abuse and neglect statutes," 49 Fed. Reg. 1627 (1984)—thereby requiring under the guise of nondiscrimination a service which state law denies to the nonhandicapped.[26]

The complaint-handling process the Secretary would impose on unwilling state agencies is totally foreign to the authority to prevent discrimination conferred on him by § 504. "Section 504 seeks to assure evenhanded treatment," *Alexander* v. *Choate*, 469 U. S., at 304; "neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation" on recipients of federal financial assistance, *Southeastern Community College* v. *Davis*, 442 U. S. 397, 411 (1979).[27] The Solicitor General also recognizes that § 504 is concerned with discrimination and with discrimination alone. In his attempt to distinguish the Secretary's 1976 determination that it "is beyond the authority of section 504" to promulgate regulations "concerning adequate and appropriate psychiatric care or safe and humane living conditions for persons institutionalized because of handicap or concerning payment of fair compensation to patients who perform work," 41 Fed. Reg. 29548, 29559, the Solicitor General explains:

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[26] JUSTICE WHITE's dissent, quoting the Secretary's explanation for these requirements, concludes that they form, in "substance," a nondiscrimination requirement. *Post*, at 663. This assertion is repetitive, not responsive. The rules governing state child protective services agencies operate independently of any provisions of state law; they go further than them in several respects; they flatly contradict them in others (*e. g.*, confidentiality); and they do not accommodate the revision, modification, or repeal of state laws. To say that the Secretary can give detailed marching orders to state agencies upon discovering that both the agencies and HHS are working toward the same general objective—at least when defined with sufficient abstractness—would countenance a novel and serious intrusion on state autonomy.

[27] See *Southeastern Community College* v. *Davis*, 442 U. S., at 410 (language and structure of 1973 Rehabilitation Act recognizes "the distinction between . . . evenhanded treatment . . . and affirmative efforts").

> "This conclusion of course was consistent with the fact that, as relevant here, Section 504 is essentially concerned only with discrimination in the *relative* treatment of handicapped and nonhandicapped persons and does not confer any *absolute* right to receive particular services or benefits under federally assisted programs." Brief for Petitioner 40, n. 33.

See also 48 Fed. Reg. 30846 (1983) ("Section 504 is in essence an equal treatment, non-discrimination standard").[illegible]

The Final Rules, however, impose just the sort of absolute obligation on state agencies that the Secretary had previously disavowed. The services state agencies are required to make available to handicapped infants are in no way tied to the level of services provided to similarly situated nonhandicapped infants. Instead, they constitute an "*absolute* right to receive particular services or benefits" under a federally assisted program. Even if a state agency were scrupulously impartial as between the protection it offered handicapped and nonhandicapped infants, it could still be denied federal funding for failing to carry out the Secretary's mission with sufficient zeal.

It is no answer to state, as does the Secretary, that these regulations are a necessary "'metho[d] . . . to give reasonable assurance' of compliance." 49 Fed. Reg. 1627 (1984) (quoting 45 CFR § 80.4(b), which requires state agencies to

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[illegible] The Secretary notes that "by enacting section 504 Congress intended to eliminate all of the 'many forms of potential discrimination' against handicapped people through 'the establishment of a broad governmental policy.' S. Rep. No. 1297, 93d Cong., 2d Sess. 38 (1974)." 49 Fed. Reg. 1636 (1984). But no matter how broad the prohibition contained in § 504 may be, what it prohibits is discrimination.

report on their compliance with Title VI). For while the Secretary can require state agencies to document their *own* compliance with § 504, nothing in that provision authorizes him to commandeer state agencies to enforce compliance by *other* recipients of federal funds (in this instance, hospitals). State child protective services agencies are not field offices of the HHS bureaucracy, and they may not be conscripted against their will as the foot soldiers in a federal crusade.[29] As we stated in *Alexander* v. *Choate*, 469 U. S., at 307, "nothing in the pre- or post-1973 legislative discussion of § 504 suggests that Congress desired to make major inroads on the States' longstanding discretion to choose the proper mix" of services provided by state agencies.

VIII

Section 504 authorizes any head of an Executive Branch agency—regardless of his agency's mission or expertise—to promulgate regulations prohibiting discrimination against the handicapped. See S. Rep. No. 93-1297, pp. 39-40 (1974).[30] As a result of this rulemaking authority, the Secretary of

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[29] Important principles of federalism are implicated by any "federal program that compels state agencies . . . to function as bureaucratic puppets of the Federal Government." *FERC* v. *Mississippi*, 456 U. S. 742, 783 (1982) (opinion of O'CONNOR, J.).

[30] Twenty-seven agencies, including the National Endowment for the Arts, the Nuclear Regulatory Commission, and the Tennessee Valley Authority, have promulgated regulations forbidding discrimination on the basis of handicap in programs or activities receiving federal financial assistance. The Department of Housing and Urban Development has issued a proposed rulemaking. See Jones & Wolfe, Regulations Promulgated Pursuant to Section 504 of the Rehabilitation Act of 1973: A Brief History and Present Status 8-9 (Congressional Research Service, Feb. 28, 1986). There is thus not the same basis for deference predicated on expertise as we found with respect to the Environmental Protection Agency's interpretation of the 1977 Clean Air Act Amendments in *Chevron U. S. A. Inc.* v. *Natural Resources Defense Council, Inc.*, 467 U. S., at 842-845, and with respect to the Federal Reserve Board's construction of the Bank Holding Act in *Board of Governors, FRS* v. *Investment Company Inst.*, 450 U. S. 46, 56, and n. 21 (1981).

HHS has "substantial leeway to explore areas in which discrimination against the handicapped pos[es] particularly significant problems and to devise regulations to prohibit such discrimination." *Alexander* v. *Choate*, 469 U. S., at 304, n. 24.

Even according the greatest respect to the Secretary's action, however, deference cannot fill the lack of an evidentiary foundation on which the Final Rules must rest. The Secretary's basis for federal intervention is perceived discrimination against handicapped infants in violation of § 504, and yet the Secretary has pointed to no evidence that such discrimination occurs. Neither the fact that regulators generally may rely on generic information in a particular field or comparable experience gained in other fields, nor the fact that regulations may be imposed for preventative or prophylactic reasons, can substitute for evidence supporting the Secretary's own chosen rationale. For the principle of agency accountability recited earlier means that "an agency's action must be upheld, if at all, on the basis articulated by the agency itself." *Motor Vehicle Mfrs. Assn.* v. *State Farm Mut. Automobile Ins. Co.*, 463 U. S., at 50 (citations omitted).[31]

The need for a proper evidentiary basis for agency action is especially acute in this case because Congress has failed to indicate, either in the statute or in the legislative history, that it envisioned federal superintendence of treatment decisions traditionally entrusted to state governance. "[W]e must assume that the implications and limitations of our federal system constitute a major premise of all congressional legislation, though not repeatedly recited therein." *United States* v. *Gambling Devices*, 346 U. S. 441, 450 (1953) (opinion of Jackson, J.).[32] Congress therefore "will not be deemed to have significantly changed the federal-state balance," *United States* v. *Bass*, 404 U. S. 336, 349 (1971)—or to have authorized its delegates to do so—"unless otherwise the purpose of the Act would be defeated," *FTC* v. *Bunte Bros., Inc.*, 312 U. S. 349, 351 (1941).[33] Although the nondiscrimi-

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[31] Accord, *American Textile Mfrs. Institute, Inc.* v. *Donovan*, 452 U. S. 490, 539 (1981); *Burlington Truck Lines, Inc.* v. *United States*, 371 U. S. 156, 168 (1962); *SEC* v. *Chenery Corp.*, 332 U. S. 194, 196 (1947); *SEC* v. *Chenery Corp.*, 318 U. S. 80, 87 (1943).

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[32] See Frankfurter, Some Reflections on the Reading of Statutes, 47 Colum. L. Rev. 527, 540 (1947) ("The underlying assumptions of our dual form of government, and the consequent presuppositions of legislative draftsmanship which are expressive of our history and habits, cut across what might otherwise be the implied range of legislation").

[33] Cf. *Heublein, Inc.* v. *South Carolina Tax Comm'n*, 409 U. S. 275, 281–282 (1972) ("'[U]nless Congress conveys its purpose clearly, it will not be deemed to have significantly changed the Federal-State balance.'" (quoting *United States* v. *Bass*, 404 U. S., at 349); *Davies Warehouse Co.* v. *Bowles*, 321 U. S. 144, 152 (1944) ("Where Congress has not clearly indicated a purpose to precipitate conflict [between federal agencies and state authority] we should be reluctant to do so by decision" (footnote omitted)); *Penn Dairies, Inc.* v. *Milk Control Comm'n*, 318 U. S. 261, 275 (1943) ("An unexpressed purpose of Congress to set aside statutes of the states regulating their internal affairs is not lightly to be inferred and ought not to be implied where the legislative command, read in the light of its history, remains ambiguous"); *FTC* v. *Bunte Bros., Inc.*, 312 U. S., at 354–355 ("The construction of § 5 [of the Federal Trade Commission Act] urged by the Commission would thus give a federal agency pervasive control over myriads of local businesses in matters heretofore traditionally left to local custom or local law. . . . An inroad upon local conditions and local standards of such far-reaching import as is involved here, ought to await a clearer mandate from Congress"); *Apex Hosiery Co.* v. *Leader*, 310 U. S. 469, 513 (1940) ("The maintenance in our federal system of a proper distribution between state and national governments of police authority and of remedies private and public for public wrongs is of far-reaching importance. An intention to disturb the balance is not lightly to be imputed to Congress"); *United States* v. *Altobella*, 442 F. 2d 310, 313–316 (CA7 1971); 3 C. Sands, Sutherland on Statutory Construction § 62.01, p. 64 (4th ed. 1974) ("[T]he rule of strict construction [of statutes in derogation of sovereignty] serves a quasi-constitutional purpose in our federal system of split sovereignty by helping to secure both levels of sovereign power against encroachment by each other" (footnote omitted)).

The legislative history of the Rehabilitation Act does not support the notion that Congress intended intervention by federal officials into treatment nation mandate of § 504 is cast in language sufficiently broad to suggest that the question is "not one of authority, but of its appropriate exercise[,] [t]he propriety of the exertion of the authority must be tested by its relation to the purpose of the [statutory] grant and with suitable regard to the principle that whenever the federal power is exerted within what would otherwise be the domain of state power, the justification of the exercise of the federal power must clearly appear." *Florida* v. *United States*, 282 U. S. 194, 211–212 (1931). Accord, *Chicago, M., St. P. & P. R. Co.* v. *Illinois*, 355 U. S. 300, 306 (1958). That is, "it must appear that there are findings, supported by evidence, of the essential facts . . . which would justify [the Secretary's] conclusion." *Florida* v. *United States*, 282 U. S., at 212. The administrative record does not contain the reasoning and evidence that is necessary to sustain federal intervention into a historically state-administered decisional process that appears—for lack of any evidence to the contrary—to be functioning in full compliance with § 504.

The history of these regulations exposes the inappropriateness of the extraordinary deference—virtually a *carte blanche*—requested by the Government. The Secretary's

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decisions traditionally left by state law to concerned parents and the attending physicians or, in exceptional cases, to state agencies charged with protecting the welfare of the infant. As the Court of Appeals noted, there is nothing in the legislative history that even remotely suggests that Congress contemplated the possibility that "section 504 could or would be applied to treatment decisions, involving defective newborn infants." 729 F. 2d 144, 159 (1984).

"'As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking, nor were representatives of parents or spokesmen for religious beliefs that would be affected heard.'" *Id.*, at 158 (quoting *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp., at 401).

present reading of § 504 has evolved only after previous, patently erroneous interpretations had been found wanting.[34] The checkered history of these regulations began in 1982, when the Department notified hospitals that they would violate § 504 if they "allow[ed] an infant" to remain in their care after "the infant's parents or guardian [had withheld consent to] treatment or nourishment discriminatorily." 47 Fed. Reg. 26027. By the time the Proposed Rules were announced one year later, the Secretary had abandoned that construction. But the Department substituted the equally untenable view that "the basic provision of nourishment, fluids, and routine nursing care" was "not an option for medical judgment" and that "[t]he decision to forego medical treatment of a correctable life-threatening defect because an infant also suffers from a permanent irremediable handicap that is not life-threatening, such as mental retardation, is a violation of Section 504," insinuating by omission that lack of parental consent did not alter the hospital's obligation to provide corrective surgery. 48 Fed. Reg. 30852, 30847 (1983). Although the preamble to the Final Rules corrects the prior erroneous signals from the Department that § 504 authorizes it to override parental decisions and to save the lives of handicapped infants, it persists in advocating federal regulation on the basis of treatment denials precipitated by refusals of parental consent and on the ground that its experience with the Baby Doe hotline has demonstrated that "the assumption that handicapped infants will receive medically beneficial treatment is not always justified." 49 Fed. Reg. 1646 (1984).

This response, together with its previous remarks, makes irresistible the inference that the Department regards its mission as one principally concerned with the quality of medical care for handicapped infants rather than with the implementation of § 504. We could not quarrel with a decision by the Department to concentrate its finite compliance resources on instances of life-threatening discrimination rather than instances in which merely elective care has been withheld. Cf. *Heckler* v. *Chaney*, 470 U. S. 821 (1985). But nothing in the statute authorizes the Secretary to dispense with the law's focus on discrimination and instead to employ federal resources to save the lives of handicapped newborns, without regard to whether they are victims of discrimination by recipients of federal funds or not. Section 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children. We may assume that the "qualified professionals" employed by the Secretary may make valuable contributions in particular cases, but neither that assumption nor the sincere conviction that an immediate "on-site investigation" is "necessary to protect the life or health of a handicapped individual" can enlarge the statutory powers of the Secretary.

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[34] "The fact that the agency's interpretation "has been neither consistent nor longstanding . . . substantially diminishes the deference to be given to HEW's [now HHS's] present interpretation of the statute." *Southeastern Community College* v. *Davis*, 442 U. S., at 412, n. 11 (citing *General Electric Co.* v. *Gilbert*, 429 U. S. 125, 143 (1976)).

The administrative record demonstrates that the Secretary has asserted the authority to conduct on-site investigations, to inspect hospital records, and to participate in the decisional process in emergency cases in which there was no colorable basis for believing that a violation of § 504 had occurred or was about to occur. The District Court and the Court of Appeals correctly held that these investigative actions were not authorized by the statute and that the regulations which purport to authorize a continuation of them are invalid.

The judgment of the Court of Appeals is affirmed.

It is so ordered.

CHIEF JUSTICE BURGER concurs in the judgment.

JUSTICE REHNQUIST took no part in the consideration or decision of this case.

JUSTICE WHITE, with whom JUSTICE BRENNAN joins and with whom JUSTICE O'CONNOR joins as to Parts I, II, IV, and V, dissenting.

Section 504 of the Rehabilitation Act of 1973 forbids discrimination solely on the basis of handicap in programs or activities receiving federal financial assistance. The issue before us is whether the Secretary of Health and Human Services has any authority under the Act to regulate medical treatment decisions concerning handicapped newborn infants. Relying on its prior decision in *United States* v. *University Hospital*, 729 F. 2d 144 (CA2 1984), the Court of Appeals held that the Secretary was without power in this respect and affirmed a decision of the District Court that § 504 does not extend so far and that the Secretary may not regulate such decisions in any manner.

Although it is my view that we granted certiorari to address this issue, the plurality avoids it by first erroneously reading the decision below as enjoining only the enforcement of specific regulations and by then affirming on the basis that the promulgation of the regulations did not satisfy established principles of administrative law, a matter that the Court of Appeals had no occasion to, and did not, discuss. With all due respect, I dissent.

I

The plurality's initial and fundamental error is its statement that the only question presented here is the specific question whether the four mandatory provisions of the Final Rules issued by the Secretary are authorized by § 504. This conclusion misconstrues the opinion and judgment of the Court of Appeals. The plurality concedes that the District Court's judgment on its face did not stop with enjoining the enforcement of the final regulations. *Ante*, at 625–626, n. 11. In fact, the District Court permanently enjoined the Secretary from implementing the final regulations and also from "continuing or undertaking any other actions to investigate or regulate treatment decisions involving impaired newborn infants taken under authority of Section 504, including pending investigation and other enforcement actions." App. to Pet. for Cert. 51a–52a. This broad injunction ousted the Secretary from the field entirely and granted the precise relief sought by the complaint, which was filed after *University Hospital* and which sought to take full advantage of that decision.[1] The Court of Appeals affirmed and in no way modified the injunction that the District Court had entered. In doing so, the Court of Appeals relied on its previous determination in *University Hospital* that the Secretary had no statutory authority to regulate medical treatment decisions regarding newborn infants. See App. to Pet. for Cert. 2a–3a.[2]

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[1] I disagree with the plurality's conclusion that "[t]he complaints in this case did not challenge the Department's authority to regulate all treatment decisions, but more precisely the mandatory provisions of the Final Rules and enforcement activity along those lines but undertaken pursuant to the Department's 'general authority' to enforce § 504." *Ante*, at 625, n. 11. Although focusing most extensively on the regulations and pending HHS investigations, the complaint specifically cited the *University Hospital* holding that "Section 504 [does] not apply to 'treatment decisions involving defective newborn infants.'" App. 138. The complaint also specifically requested that the District Court "issue a preliminary and permanent injunction prohibiting the defendant from enforcing her final rule embodied in 45 CFR § 84.55, 49 Fed. Reg. 1622, *et seq.* (Jan. 12, 1984), and prohibiting defendant from otherwise acting pursuant to the claimed authority of Section 504 of the Rehabilitation Act of 1973 in regard to the medical treatment of infants with birth defects." *Id.*, at 159. The complaint thus requested both invalidation of the regulations and an injunction against all other actions by the Secretary in this area.

[2] The Court of Appeals' brief order affirming the District Court's judgment, although characterizing that judgment generally as having struck down the regulations, cited *University Hospital* and made no changes in the broad relief awarded by the District Court. The Court of Appeals

It is true that the regulations themselves were invalidated and their enforcement enjoined. This result, however, was directly compelled by the *University Hospital* conclusion that the Secretary was without power to issue any regulations whatsoever that dealt with infants' medical care, and it did not comprise the whole relief awarded by the District Court and affirmed by the Court of Appeals. I thus see no justification for the plurality's distortion of the Court of Appeals' affirmance of the District Court's all-inclusive injunction, which, like *University Hospital*, now represents the law in the Second Circuit.[3] We should resolve the threshold statutory question that this case and *University Hospital* clearly pose—namely, whether the Secretary has any authority at all under the Act to regulate medical care decisions with respect to the handicapped newborn.[4]

II

Section 504 of the Act, which was construed in *University Hospital*, provides:

> "No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title,

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gave absolutely no indication that it was construing the District Court's judgment one whit less broadly than that judgment's language indicated. Nowhere, therefore, is there a justification for the plurality's reconstructive reading of the Court of Appeals' judgment.

[3] I note in this regard that the parties as well do not appear to have contemplated the more limited reading of the judgment below adopted by the plurality. See Brief for Petitioner 9; Brief for Respondents American Hospital Association et al. 4; Brief for Respondents American Medical Association et al. 14.

[4] I would not avoid the issue of the validity of *University Hospital* even if the judgment below were limited to invalidation of these regulations. Given that the judgment below, whether it extends as far as *University Hospital* or not, was based on the *University Hospital* view that *all* regulation of medical treatment decisions is outside the Secretary's § 504 authority because of the nature of those decisions, I believe that the better approach here would be for the Court to determine the correctness of *University Hospital* in any case.

> shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 29 U. S. C. § 794.

After determining that § 706(7), which defines handicapped persons, is not limited to adults and includes the newborn, the Court of Appeals in *University Hospital* construed the "otherwise qualified" language of § 504 to limit the reach of the section to situations in which the handicap is "unrelated to, and thus improper to consideration of, the services in question." 729 F. 2d, at 156.[5] This, concluded the Court of Appeals, would exclude most handicapped newborns because their handicaps are not normally irrelevant to the need for medical services. Furthermore, the Court of Appeals thought that the "otherwise qualified" limitation should not be applied in the "comparatively fluid context of medical treatment decisions" because "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory.'" *Id.*, at 156–157.

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[5] The Court of Appeals first addressed and reserved the question whether the hospital or its functions comprised a program or activity receiving federal financial assistance. Noting that this was a fact-specific inquiry, cf. *Grove City College* v. *Bell*, 465 U. S. 555 (1984), the Court of Appeals assumed that the entire hospital was covered by § 504 and proceeded to consider "whether, assuming the entire hospital is covered by section 504, the statute authorizes the type of investigation initiated here." 729 F. 2d, at 151.

I also do not consider whether or under what circumstances hospitals or hospital neonatal programs may constitute programs or activities receiving federal financial assistance. The judgment of the District Court which was affirmed by the Court of Appeals does not set forth guidelines for interpreting this language in this context: It merely enjoins actions directed at such programs or activities. The regulations as well simply adopt the statutory language without interpreting it. Thus, I assume here that the § 504 strictures would be applied only to appropriate programs or activities, and I therefore would leave discussion of this fact-specific issue for further proceedings. I would not now hold that § 504 may never apply on this basis.

Having identified these perceived incongruities between the language of § 504 and the potential regulation of medical decisions regarding handicapped newborns, the Court of Appeals concluded that "[b]efore ruling that congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute." *Id.*, at 157. Thus, the Court of Appeals turned to the legislative history, where it again found nothing to persuade it that Congress intended § 504 to apply to medical treatment of handicapped infants and hence to enter a field so traditionally occupied by the States. Neither did it consider the current administrative interpretation of § 504 to be a longstanding agency construction calling for judicial deference. In the Court of Appeals' view, therefore, the section was inapplicable to medical treatment decisions regarding the newborn absent some further indication of congressional intent.

I disagree with this conclusion, which the Court of Appeals adhered to in the case before us now. Looking first at the language of the statute, I agree with the Court of Appeals' preliminary conclusion that handicapped newborns are handicapped individuals covered by the Act. There is no reason for importing an age limitation into the statutory definition, and this Court has previously stated that "§ 504 protects handicapped persons of all ages from discrimination in a variety of programs and activities receiving federal financial assistance." *Smith* v. *Robinson*, 468 U. S. 992, 1016–1017 (1984).[4] This leaves the critical question whether a handicapped infant can ever be "otherwise qualified" for medical treatment and hence possibly subjected to unlawful discrimination when he or she is denied such treatment.[7]

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[4] Although infants with birth defects are clearly handicapped individuals covered by § 504, there is one manner in which they may differ from most other handicapped individuals for § 504 purposes. Specifically, they may have a combination of conditions—some of which are medically correctable and some of which are not. In older handicapped individuals, medically correctable conditions may have been corrected so that only irreparable handicapping conditions remain. In a newborn infant, however, both correctable and incorrectable conditions may exist. Thus, since both of these

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may interfere with major life activities, both types of conditions may be considered to be handicaps. In this context, however, it might make more sense to consider as handicaps only those conditions that cannot be medically treated to the point that they will not impair major life activities. For such correctable conditions would not be likely to cause the infant to be regarded as handicapped. In any case, I believe that defining an infant's handicap may well be a delicate problem and one that deserves some consideration.

[7] It would appear that for an infant to be qualified for treatment his or her parents must have consented to such treatment. For the purposes of this discussion of whether the Court of Appeals was correct that medical treatment decisions may *never* be regulated by § 504, I assume that parental consent has been given and that the arguably discriminatory treatment decision is being made by the hospital or doctor. The Court of Appeals in *University Hospital* concentrated on the nature of these decisions in concluding that § 504 may not properly be applied, and I concentrate on that as well. That a situation in which treatment is refused where parental consent has been given may not have been shown to have arisen does not undermine this assumption here. The critical question is whether the operative provisions of § 504 may *ever* apply here given the nature of the decision.

For the purposes of addressing the Court of Appeals' *University Hospital* analysis, the most straightforward fact situation to consider is one in which the benefit provided is the medical treatment itself and in which a hospital refuses treatment in the face of parental consent. In this context, the Court of Appeals' conclusion that the nature of the decisions themselves precludes application of § 504 may be addressed with maximum simplicity. I note, however, that it may well be that the benefits provided by hospitals and doctors and covered by § 504 extend beyond treatment itself. For example, one benefit provided by hospitals and doctors to patients who cannot make their own medical treatment decisions may be medical advice in those patients' best interest to those who must ultimately make the relevant medical treatment decisions. To the extent that the provision of this benefit is a program or activity covered by the statute, I would think that the statute requires that the same advice be given to parents of a handicapped baby as to the parents of a similarly situated nonhandicapped baby. Another benefit provided may be the reporting of nontreatment to the relevant state agency in the case of a parental decision not to treat. Again, It may well be that our prior consideration of this language has implied that the Court of Appeals' construction is correct. In *Southeastern Community College* v. *Davis*, 442 U. S. 397, 406 (1979), we held that "[a]n otherwise qualified person is one who is able to meet all of a program's requirements in spite of his handicap." This formulation may be read as implying that where a handicapped person meets all of the requirements normally necessary to receive a program's benefits regardless of his or her handicap, he or she is otherwise qualified because that handicap does not interfere with and is thus irrelevant to his or her qualification for the program. Thus, the Court of Appeals' view—that refusing treatment that is called for only because of the handicapping condition cannot constitute discrimination on the basis of handicap since there will be no similarly situated nonhandicapped newborn, *i. e.*, one who needs the same treatment—draws support from our holding in *Davis* since it turns on the same underlying perception that discrimination occurs only when the handicapping condition is irrelevant to the qualification for the program.

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to the extent that the provision of this benefit is a program or activity covered by the statute, see n. 13, *infra*, I would think that § 504 requires that the hospital or doctor report nontreatment of a handicapped baby when it would report the denial of the same treatment for a nonhandicapped baby.

My conclusions in this regard are buttressed by my view of § 504's coverage in the case of a medical treatment decision regarding a black baby. If a hospital or doctor advised different or less efficacious treatment for a black baby than for a white baby, I believe that this would be discrimination under the statute. Similarly, a failure to report a parental decision not to treat because of race would seem to me to be illegally discriminatory—assuming that this decision otherwise came within the statute.

In sum, although these additional situations present the same issue as to when a handicapped baby is otherwise qualified and when such a baby is subjected to discrimination as does the direct example of a refusal to treat and although it may well be that it would be in these contexts that the statute would most likely be given effect, for simplicity's sake I have centered my discussion of *University Hospital* on the refusal-to-treat example.

Even under the Court of Appeals' interpretation of "otherwise qualified," however, it does not follow that § 504 may never apply to medical treatment decisions for the newborn. An esophageal obstruction, for example, would not be part and parcel of the handicap of a baby suffering from Down's syndrome, and the infant would benefit from and is thus otherwise qualified for having the obstruction removed in spite of the handicap. In this case, the treatment is completely unrelated to the baby's handicapping condition. If an otherwise normal child would be given the identical treatment, so should the handicapped child if discrimination on the basis of the handicap is to be avoided.[*]

It would not be difficult to multiply examples like this. And even if it is true that in the great majority of cases the handicap itself will constitute the need for treatment, I doubt that this consideration or any other mentioned by the Court of Appeals justifies the wholesale conclusion that § 504 never applies to newborn infants with handicaps. That some or most failures to treat may not fall within § 504, that discerning which failures to treat are discriminatory may be difficult, and that applying § 504 in this area may intrude into the traditional functions of the State do not support the categorical conclusion that the section may never be applied to medical decisions about handicapped infants. And surely the absence in the legislative history of any consideration of handicapped newborns does not itself narrow the reach of the statutory language. See *Jefferson County Pharmaceutical Assn.* v. *Abbott Laboratories*, 460 U. S. 150, 159–162, and n. 18 (1983). Furthermore, the broad remedial purpose of the section would be undermined by excluding handicapped infants from its coverage; and if, as the plurality indicates, *ante*, at 642–643, the Secretary has substantial leeway to explore areas in which discrimination against the handicapped poses serious problems and to devise regulations to prohibit the discrimination, it is appropriate to take note of the Secretary's present view that § 504 properly extends to the subject matter at issue here. Thus, I believe that the Court of Appeals in *University Hospital* incorrectly concluded that § 504 may never apply to medical treatment decisions concerning handicapped newborn infants. Where a decision regarding medical treatment for a handicapped newborn properly falls within the statutory provision, it should be subject to the constraints set forth in § 504. Consequently, I would reverse the judgment below.

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[*] There are substantial arguments that could be made that the Court of Appeals too narrowly read the statute. It could be argued, for example, that the benefit provided by hospitals is not defined in terms of specific treatments. Rather, the benefit is "general medical care for whatever happens to need treating." If this is the benefit, then a much broader application of the statute in this context is reasonable. Alternatively, even if the benefit is defined more narrowly, "reasonable accommodation" might require more than mere impartial dispensing of identical treatment. See *Alexander* v. *Choate*, 469 U. S. 287, 299–300, and nn. 19, 20 (1985). I need not resolve this issue of the exact meaning of § 504 and *Davis* in this context, however, because my conclusion that *University Hospital*'s broad reasoning was incorrect does not depend on it. Although I do not resolve these issues, I note that while the more expansive interpretations seem consistent with the interpretation adopted by the Secretary in the regulations, the more restrictive one does not. See 45 CFR pt. 84, Appendix C(a) (1985).

III

Having determined that the stated basis for the Court of Appeals' holding in *University Hospital* was incorrect and that the decision below cannot be supported by *University Hospital's* blanket prohibition, I would remand the case to the Court of Appeals. The respondents have, as the plurality's opinion itself demonstrates, raised significant issues aside from the threshold statutory issue presented here. There are, for example, substantial questions regarding the scope of the Secretary's statutory authority in this area and whether these particular regulations are consistent with the statute. I would decline to reach and decide these questions for the first time in this Court without the benefit of the lower courts' deliberations.[9] The plurality, however, has chosen to reach out and address one of those subsidiary issues. Because the plurality has resolved that issue in a manner that I find indefensible on its own terms, I too address it.

The plurality concludes that the four mandatory provisions of the final regulations are invalid because there is no "'rational connection between the facts found and the choice made.'" *Motor Vehicle Mfrs. Assn., Inc.* v. *State Farm Mutual Automobile Ins. Co.*, 463 U. S. 29, 43 (1983) (quoting *Burlington Truck Lines, Inc.* v. *United States*, 371 U. S. 156, 168 (1962)). The basis for this conclusion is the plurality's perception that two and only two wholly discrete categories of decisions are the object of the final regulations: (1) decisions made by hospitals to treat or not treat where parental consent has been given and (2) decisions made by hospitals to refer or not to refer a case to the state child protective services agency where parental consent has been withheld.[10]

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[9] In addition, although the Secretary did not brief the merits of the respondents' claim that the regulations are invalid because arbitrary and capricious, the Secretary did indicate his view that this claim in its current form is not properly in the case and that it is inadequate on its face. See Reply Brief for Petitioner 16, n. 6.

Specifically, the Secretary first asserts that the respondents' argument as to the lack of factual basis involving situations in which parents *have* consented to treatment was not raised in the complaint. See App. 146 (challenging lack of showing of instances where "erroneous" parental decisions were made and where medical authorities did not take proper measures under state law). Thus, the Secretary contends that the first major claim addressed and relied on by the plurality was never properly raised. Second, the Secretary contends that these are interpretative regulations that impose no new substantive duties, see 49 Fed. Reg. 1628 (1984), and that no factual basis for their issuance need therefore be given. *Cf.* 5 U. S. C. § 553(b).

These contentions, although not perhaps representing a procedural bar to our reaching this claim, see *ante*, at 629, n. 14, do provide an additional sign that the plurality's resolution of this case rests on shaky ground.

[10] At this point in the case, as the plurality observes, all parties concerned agree that parental decisions are not included in § 504's application. See *ante*, at 630.

Since the Secretary has not specifically pointed to discriminatory actions that provably resulted from either of these two specific types of decisions, the plurality finds that the Secretary's conclusion that discrimination is occurring is unsupported factually. The plurality's characterization of the Secretary's rationale, however, oversimplifies both the complexity of the situations to which the regulations are addressed and the reasoning of the Secretary.

First, the Secretary's proof that treatment is in fact being withheld from handicapped infants is unquestioned by the plurality. It is therefore obvious that whoever is making them, *decisions* to withhold treatment from such infants are in fact being made. This basic understanding is critical to the Secretary's further reasoning, and the discussion accompanying the proposed regulations clearly indicates that this was the Secretary's starting point. See 48 Fed. Reg. 30847–30848 (1983). Proceeding with this factual understanding, the next question is whether such withholding of treatment constitutes prohibited discrimination under § 504 in some or all situations. It is at this point that the plurality errs. In the plurality's view, only two narrow paradigmatic types of decisions were contemplated by the Secretary as potentially constituting discrimination in violation of the statute. See *ante*, at 628–629. The plurality does not explain, however, precisely what in the Secretary's discussion gives rise to this distillation, and my reading of the explanation accompanying the regulations does not leave me with so limited a view of the Secretary's concerns.

The studies cited by the Secretary in support of the regulations and other literature concerning medical treatment in this area generally portray a decisionmaking process in which the parents and the doctors and often other concerned persons as well are involved—although the parental decision to consent or not is obviously the critical one.[11] Thus, the parental consent decision does not occur in a vacuum. In fact, the doctors (directly) and the hospital (indirectly) in most cases participate in the formulation of the final parental decision and in many cases substantially influence that decision.[12] Consequently, discrimination against a handicapped infant may assume guises other than the outright refusal to treat once parental consent has been given. Discrimination may occur when a doctor encourages or fails to discourage a parental decision to refuse consent to treatment for a handicapped child when the doctor would discourage or actually oppose a parental decision to refuse consent to the same treatment for a nonhandicapped child. Or discrimination may occur when a doctor makes a discriminatory treatment recommendation that the parents simply follow. Alternatively, discrimination may result from a hospital's explicit laissez-faire attitude about this type of discrimination on the part of doctors.

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[11] See, *e. g.*, Duff & Campbell, Moral and Ethical Dilemmas in the Special-Care Nursery, 289 N. Eng. J. Med. 890 (1973). See also Gross,

Contrary to the plurality's constrained view of the Secretary's justification for the regulations, the stated basis for those regulations reveals that the Secretary was cognizant of this more elusive discrimination. For example, the evidence cited most extensively by the Secretary in his initial proposal of these regulations was a study of attitudes of practicing and teaching pediatricians and pediatric surgeons. See 48 Fed. Reg. 30848 (1983) (citing Shaw, Randolph, & Manard, Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons, 60 Pediatrics 588 (1977)). This study indicated that a substantial number of these doctors (76.8% of pediatric surgeons and 49.5% of pedi-

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Cox, Tatyrek, Pollay, & Barnes, Early Management and Decision Making for the Treatment of Myelomeningocele, 72 Pediatrics 450 (1983).

[12] Presumably, the program or activity that § 504 would apply to in this context would be the hospital's neonatal program of medical care or the hospital's program of medical care generally. In either case, actions of both doctors and hospitals that cause or permit discriminatory decisions that are taken as part of the program or activity would be subject to § 504's constraints.

atricians) would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia if the infant also had . . . Down's syndrome." *Id.*, at 590. It also indicated that a substantial minority (23.6% of pediatric surgeons and 13.2% of pediatricians) would in fact encourage parents to refuse consent to surgery in this situation and that only a small minority (3.4% of pediatric surgeons and 15.8% of pediatricians) would attempt to get a court order mandating surgery if the parents refused consent. In comparison, only a small minority (7.9% of pediatric surgeons and 2.6% of pediatricians) would acquiesce in parental refusal to treat intestinal atresia in an infant with no other anomaly. And a large majority (78.3% of pediatric surgeons and 88.4% of pediatricians) would try to get a court order directing surgery if parental consent were withheld for treatment of a treatable malignant tumor. The Secretary thus recognized that there was evidence that doctors would act differently in terms of attempts to affect or override parental decisions depending on whether the infant was handicapped.

Based on this evidence, the Secretary conceded that "[t]he full extent of discriminatory and life-threatening practices toward handicapped infants is not yet known" but concluded "that for even a single infant to die due to lack of an adequate notice and complaint procedure is unacceptable." 48 Fed. Reg. 30847 (1983). Thus, the Secretary promulgated the regulations at issue here. These regulations, in relevant part, require that a notice of the federal policies against discrimination on the basis of handicap be posted in a place where a hospital's health care professionals will see it. This requirement is, as the Secretary concluded, "[c]onsistent with the Department's intent to target the notice to nurses and other health care professionals." App. 25. The notice requirement, therefore, may reasonably be read as aimed at fostering an awareness by health care professionals of their responsibility not to act in a discriminatory manner with respect to medical treatment decisions for handicapped infants.

The second requirement of the regulations, that state agencies provide mechanisms for requiring and reporting medical neglect of handicapped children, is also consistent with the Secretary's focus on discrimination in the form of discriminatory reporting.[13]

I therefore perceive a rational connection between the facts found by the Secretary and the regulatory choice made. The Secretary identified an existing practice that there was reason to believe resulted from discrimination on the basis of handicap. Given this finding, the amorphous nature of much of the possible discrimination, the Secretary's profession that the regulations are appropriate no matter how limited the problem,[14] and the focus of the regulations on loci where unlawful discrimination seems most likely to occur and on persons likely to be responsible for it, I conclude that these regulations are not arbitrary and capricious and that the Court errs in striking them down on that basis. Although the Secretary's path here may be marked with "'less than ideal clarity,'" we will uphold such a decision "'if the agency's path may reasonably be discerned.'" *Motor Vehicles Mfrs. Assn.*, 463 U. S., at 43 (quoting *Bowman Transportation, Inc.* v. *Arkansas-Best Freight System, Inc.*, 419 U. S. 281, 286 (1974)).

The plurality also objects to the regulations' requirement concerning the state protective agencies' reporting procedures on another ground. Specifically, the plurality finds that this requirement is in fact a substantive prescription rather than a prohibition of discrimination. The plurality bases this conclusion on the fact that the regulation sets forth specific procedures that must be adopted by state agencies.

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[13] The plurality reserves the question whether reporting would be a program or activity receiving federal financial assistance, *ante*, at 639, n. 25, and I follow that course.

[14] The plurality itself says that "regulations may be imposed for preventative or prophylactic reasons," *ante*, at 643, but concludes that the Secretary here proceeded based on the perception of an actual problem rather than a need for prophylactic rules. To me, however, the Secretary's statement that the rules are appropriate if necessary for even one problem situation makes the plurality's distinction in this respect questionable: The line between a prophylactic rule and a rule that draws its justification from the likely existence of even one unlawful action seems to me a very fine one.

The plurality's conclusion disregards the Secretary's explanation for this requirement. In the preamble to the proposed regulations, the Secretary explicitly stated:

> "The Department has determined that under every state's law, failure of parents to provide necessary, medically indicated care to a child is either explicitly cited as grounds for action by the state to compel treatment or is implicitly covered by the state statute. These state statutes also provide for appropriate administrative and judicial enforcement authorities to prevent such instances of medical neglect, including requirements that medical personnel report suspected cases to the state child protective services agency, agency access to medical files, immediate investigations and authority to compel treatment." 48 Fed. Reg. 30848 (1983).

This finding was repeated in the statement accompanying the final regulations:

> "Although there are some variations among state child protective statutes, all have the following basic elements: a requirement that health care providers report suspected cases of child abuse or neglect, including medical neglect; a mechanism for timely receipt of such reports; a process for administrative inquiry and investigation to determine the facts; and the authority and responsibility to seek an appropriate court order to remedy the apparent abuse and neglect, if it is found to exist." 49 Fed. Reg. 1627 (1984).

The regulations, in turn, require that the State provide these same services with respect to medical neglect of handicapped infants. See 45 CFR § 84.55(c) (1985). The only additional requirements imposed by the regulations involve provisions enabling the Department itself to review for compliance with the nondiscrimination requirements. Consequently, the regulations simply track the existing state procedures found to exist by the Secretary, requiring that funded state agencies provide those same procedures for handicapped children. The fact that the regulations specify the procedures that are necessary to ensure an absence of discrimination and do not instead speak in "nondiscrimination" terms is irrelevant. The substance of the requirement is nondiscrimination. The plurality's conclusion in this regard, however, apparently rests on a determination that implementation of a nondiscrimination mandate may be accomplished in only one form—even if the same result may be accomplished by another route. See *ante*, at 640, n. 26. I would not elevate regulatory form over statutory substance in this manner. In sum, the plurality's determination that the regulations were inadequately supported and explained as a matter of administrative law does not withstand examination of the Secretary's discussion of the underlying problem and of the contours of the regulations themselves.

IV

My disagreement with the plurality in this case does not end here, however. For even under its chosen rationale, I find its ultimate conclusion dubious. Having assiduously restricted its discussion to the validity of the regulations only, the plurality ends up concluding expansively that not only the regulations but also other investigations taken by the Secretary independent of the regulations are invalid. Thus, the Court apparently enjoins the Secretary's on-site investigations as well as "the regulations which purport to authorize a continuation of them." *Ante*, at 647. And the plurality rests this action on the conclusion that the lower courts "correctly held that these investigative actions were not authorized by the statute." *Ibid.*

I am at a loss to understand the plurality's reasoning in this respect. In construing the judgment below, the plurality appears to conclude that, although the injunction entered by the District Court and affirmed by the Court of Appeals did not purport to prohibit *all* actions by the Secretary under the statute, the injunction did in fact extend beyond merely these particular regulations. Thus, the plurality indicates that the judgment below applied as well to actions that "resemble," "parallel," or are "along [the] lines [of]" the regulations. *Ante*, at 625–626, n. 11. The plurality further defines what actions it believes the Court of Appeals and District Court contemplated: "[T]he injunction forbids continuation or initiation of regulatory and investigative activity directed at instances in which parents have refused consent to treatment and, if the Secretary were to undertake such action, efforts to seek compliance with affirmative requirements imposed on state child protective services agencies." *Ante*, at 625, n. 11.

Aside from the fact that I see absolutely nothing in either the District Court's or the Court of Appeals' judgment that would support a constrained reading of the broadly phrased relief awarded by the District Court and affirmed without modification by the Court of Appeals,[18] I have some doubt as to how different the Court's holding today is from a holding that § 504 gives HHS no authority whatsoever over decisions to treat handicapped infants. The plurality's lack of coherence on this crucial point raises substantial doubts as to the reach of the holding and as to the basis for that holding.

Finally, I am puzzled as to how and why the plurality's determination that the regulations are invalid because they are arbitrary and capricious extends to other actions not taken under the regulations. The plurality apparently would enjoin all enforcement actions by the Secretary in situations in which parents have refused to consent to treatment. See *ante*, at 625–626, n. 11. Yet it is not clear to me that the plurality's basis for invalidating these regulations would extend to all such situations. I do not see, for example, why the plurality's finding that the Secretary did not adequately support his conclusion that failures to report refusals to treat likely result from discrimination means that such a conclusion will *never* be justified. The Secretary might be able to prove that a particular hospital generally fails to report nontreatment of handicapped babies for a specific treatment where it reports nontreatment of nonhandicapped babies for the same treatment. In essence, a determination that these regulations were inadequately supported factually would not seem to be properly extended beyond actions taken pursuant to these regulations: The fact that the Secretary has not adequately justified generalized action under the regulations should not mean that individualized action in appropriate circumstances is precluded.

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[18] See nn. 1–2, *supra*, and accompanying text.

V

In sum, the plurality today mischaracterizes the judgment below and, based on that mischaracterization, is sidetracked from the straightforward issue of statutory construction that this case presents. The plurality incorrectly resolves an issue that was not fully addressed by the parties, gives no guidance to the Secretary or the other parties as to the proper construction of the governing statute, and fails adequately to explain the precise scope of the holding or how that holding is supported under the plurality's chosen rationale. From this misguided effort, I dissent.

JUSTICE O'CONNOR, dissenting.

I fully agree with JUSTICE WHITE's conclusion that the only question properly before us is whether the Court of Appeals correctly concluded that the Secretary has no power under 29 U. S. C. § 794 to regulate medical treatment decisions concerning handicapped newborn infants. I also agree that application of established principles of statutory construction and of the appropriate standard for judicial review of agency action leads inescapably to the conclusion that the Secretary has the authority to regulate in this area. Because, however, I see no need at this juncture to address the details of the regulations or to assess whether they are sufficiently rational to survive review under 5 U. S. C. §706 (2)(A), I join only parts I, II, IV, and V of JUSTICE WHITE's dissent.

Appendix I

Child Abuse Amendments of 1984

Public Law 98-457
98th Congress

An Act

To extend and improve provisions of laws relating to child abuse and neglect and adoption, and for other purposes.

Oct. 9, 1984
[H.R. 1904]

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Child Abuse Amendments of 1984".

Child Abuse Amendments of 1984.
42 USC 5101 note.

TITLE I—AMENDMENTS TO CHILD ABUSE PREVENTION AND TREATMENT ACT

Part A—Program Improvements

THE NATIONAL CENTER ON CHILD ABUSE AND NEGLECT

Sec. 101. (a) Section 2(a) of the Child Abuse Prevention and Treatment Act (42 U.S.C. 5101(a)) (hereinafter in this title referred to as "the Act") is amended by striking out "Health, Education, and Welfare" and inserting in lieu thereof "Health and Human Services"

(b) Clauses (6) and (7) of section 2(b) of the Act are amended to read as follows:

Study.

"(6) study and investigate the national incidence of child abuse and neglect and make findings about any relationship between nonpayment of child support and between various other factors and child abuse and neglect, and the extent to which incidents of child abuse and neglect are increasing in number and severity, and, within two years after the date of the enactment of the Child Abuse Amendments of 1984, submit such findings to the appropriate Committees of the Congress together with such recommendations for administrative and legislative changes as are appropriate; and

Reports.

"(7) in consultation with the Advisory Board on Child Abuse and Neglect, annually prepare reports on efforts during the preceding two-year period to bring about coordination of the goals, objectives, and activities of agencies and organizations which have responsibilities for programs and activities related to child abuse and neglect, and, not later than March 1, 1985, and March 1 of each second year thereafter, submit such a report to the appropriate Committees of the Congress.".

(c) Section 2(c) of the Act is amended by striking out "The Secretary may carry out his functions under subsection (b) of this section" and inserting in lieu thereof "The functions of the Secretary under subsection (b) of this section may be carried out".

(d) Section 2 of the Act is further amended by inserting after subsection (d) the following new subsection:

"(e) No funds appropriated under this Act for any grant or contract may be used for any purpose other than that for which such funds were specifically authorized.".

DEFINITIONS

Post, p. 1752. SEC. 102. Section 3 of the Act is amended—

(1) by inserting "(including any employee of a residential facility or any staff person providing out-of-home care)" after "by a person";

(2) by striking out the period at the end thereof and inserting in lieu thereof a semicolon; and

(3) by adding at the end thereof the following new clause:

"(2)(A) the term 'sexual abuse' includes—

"(i) the employment, use, persuasion, inducement, enticement, or coercion of any child to engage in, or having a child assist any other person to engage in, any sexually explicit conduct (or any simulation of such conduct) for the purpose of producing any visual depiction of such conduct, or

"(ii) the rape, molestation, prostitution, or other such form of sexual exploitation of children, or incest with children,

under circumstances which indicate that the child's health or welfare is harmed or threatened thereby, as determined in accordance with regulations prescribed by the Secretary; and

"(B) for the purpose of this clause, the term 'child' or 'children' means any individual who has not or individuals who have not attained the age of eighteen.".

DEMONSTRATION OR SERVICE PROGRAMS AND PROJECTS

Grants. 42 USC 5103. SEC. 103. (a) Section 4(b)(2)(E) of the Act is amended by striking out "his" and inserting in lieu thereof "and the child's".

(b) Section 4(b)(3) of the Act is amended to read as follows:

Waiver. "(3)(A) Subject to subparagraph (B) of this paragraph, any State which on the date of enactment of the Child Abuse Amendments of

Ante, p. 1749. 1984 does not qualify for assistance under this subsection may be granted a waiver of any requirement under paragraph (2) of this subsection—

"(i) for a period of not more than one year, if the Secretary makes a finding that such State is making a good-faith effort to comply with any such requirement, and for a second one-year period if the Secretary makes a finding that such State is making substantial progress to achieve such compliance; or

"(ii) for a nonrenewable period of not more than two years in the case of a State the legislature of which meets only biennially, if the Secretary makes a finding that such State is making a good-faith effort to comply with any such requirement.

"(B) No waiver under subparagraph (A) may apply to any require-

Post, p. 1752. ment under paragraph (2)(K) of this subsection.".

(c) Section 4 of the Act is further amended—

(1) by redesignating subsection (e) as subsection (f); and

(2) by inserting after subsection (d) the following new subsection:

"(e) The Secretary, in consultation with the Advisory Board on Child Abuse and Neglect, shall ensure that a proportionate share of assistance under this Act is available for activities related to the prevention of child abuse and neglect.".

AUTHORIZATION OF APPROPRIATIONS

SEC. 104. (a) Section 5(a) of the Act is amended— 42 USC 5104.

(1) by striking out "(a)" after "SEC. 5.";

(2) by inserting after the first sentence the following new sentence: "There are hereby further authorized to be appropriated for the purposes of this Act $33,500,000 for fiscal year 1984, $40,000,000 for fiscal year 1985, $41,500,000 for fiscal year 1986, and $43,000,000 for fiscal year 1987."; and

(3) in the second sentence by striking out "this section" and all that follows through the end of such subsection, and inserting in lieu thereof "this section except as provided in the succeeding sentence, (A) not less than $9,000,000 shall be available in each fiscal year to carry out section 4(b) of this Act (relating to State grants), (B) not less than $11,000,000 shall be available in each fiscal year to carry out sections 4(a) (relating to demonstration or service projects), 2(b)(1) and 2(b)(3) (relating to information dissemination), 2(b)(5) (relating to research), and 4(c)(2) (relating to training, technical assistance, and information dissemination) of this Act, giving special consideration to continued funding of child abuse and neglect programs or projects (previously funded by the Department of Health and Human Services) of national or regional scope and demonstated effectiveness, (C) $5,000,000 shall be available in each such year for grants and contracts under section 4(a) for identification, treatment, and prevention of sexual abuse, and (D) $5,000,000 shall be available in each such year for the purpose of making additional grants to the States to carry out the provisions of section 4(c)(1) of this Act. With respect to any fiscal year in which the total amount appropriated under this section is less than $30,000,000, funds shall first be available as provided in clauses (A) and (B) in the preceding sentence and of the remainder one-half shall be available as provided for in clause (C) and one-half as provided for in clause (D) in the preceding sentence.".

42 USC 5103. 42 USC 5101. *Post*, p. 1753.

(b) Section 5(b) of the Act is repealed. 42 USC 5104.

ADVISORY BOARD ON CHILD ABUSE AND NEGLECT

SEC. 105. (a) The first sentence of section 6(a) of the Act is amended by striking out "including" and all that follows thereafter through "Administration,". 42 USC 5105.

(b) Section 6(a) of the Act is further amended by inserting at the end thereof the following sentence: "The Advisory Board may be available, at the Secretary's request, to assist the Secretary in coordinating adoption-related activities of the Federal Government.".

(c)(1) Section 6(b) of the Act is repealed.

(2) Subsection (c) of section 6 of the Act is redesignated as subsection (b).

COORDINATION

SEC. 106. Section 7 of the Act is amended by striking out "between" and inserting in lieu thereof "among". 42 USC 5106.

PART B—SERVICES AND TREATMENT FOR DISABLED INFANTS

NEW DEFINITION

42 USC 5102

SEC. 121. Section 3 of the Act is further amended—

(1) by striking out "this Act the term 'child abuse and neglect' " and inserting in lieu thereof the following: "This Act—

"(1) the term 'child abuse and neglect' ";

(2) by striking out the period at the end thereof and inserting in lieu thereof a semicolon and the word "and"; and

(3) by adding after clause (2) (as added by section 102(3) of this Act) the following new clause:

"(3) the term 'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survivial of the infant and the treatment itself under such circumstances would be inhumane.".

NEW BASIC STATE GRANT REQUIREMENT

SEC. 122. Section 4(b)(2) of the Act (42 U.S.C. 5103(b)(2)) is amended—

(1) by striking out "and" at the end of clause (I);

(2) by striking out the period at the end of clause (J) and inserting in lieu thereof a semicolon and the word "and"; and

(3) by inserting after clause (J) the following new clause:

Ante, p. 1749.

"(K) within one year after the date of the enactment of the Child Abuse Amendments of 1984, have in place for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.".

ADDITIONAL STATE GRANTS AND ASSISTANCE FOR TRAINING, TECHNICAL ASSISTANCE, AND CLEARINGHOUSE ACTIVITIES

SEC. 123. (a) Section 4 of the Act is further amended by—

42 USC 5103.

(1) redesignating subsection (c) as subsection (d), subsection (d) as subsection (e), and subsection (e) as subsection (f); and

(2) inserting after subsection (b) the following new subsection:

Public information.

"(c)(1) The Secretary is authorized to make additional grants to the States for the purpose of developing, establishing, and operating or implementing—

"(A) the procedures or programs required under clause (K) of subsection (b)(2) of this section;

Ante, p. 1752.

"(B) information and education programs or training programs for the purpose of improving the provision of services to disabled infants with life-threatening conditions for (i) professional and paraprofessional personnel concerned with the welfare of disabled infants with life-threatening conditions, including personnel employed in child protective services programs and health-care facilities, and (ii) the parents of such infants; and

"(C) programs to help in obtaining or coordinating necessary services, including existing social and health services and financial assistance for families with disabled infants with life-threatening conditions, and those services necessary to facilitate adoptive placement of such infants who have been relinquished for adoption.

Contracts with U.S.

"(2)(A) The Secretary shall provide, directly or through grants or contracts with public or private nonprofit organizations, for (i) training and technical assistance programs to assist States in developing, establishing, and operating or implementing programs and procedures meeting the requirements of clause (K) of subsection (b)(2) of this section; and (ii) the establishment and operation of national and regional information and resource clearinghouses for the purpose of providing the most current and complete information regarding medical treatment procedures and resources and community resources for the provision of services and treatment for disabled infants with life-threatening conditions (including compiling, maintaining, updating, and disseminating regional directories of community services and resources (including the names and phone numbers of State and local medical organizations) to assist parents, families, and physicians and seeking to coordinate the availability of appropriate regional education resources for health-care personnel).

"(B) Not more than $1,000,000 of the funds appropriated for any fiscal year under section 5 of this Act may be used to carry out this paragraph.

42 USC 5104.

"(C) Not later than 210 days after the date of the enactment of the Child Abuse Amendments of 1984, the Secretary shall have the capability of providing and begin to provide the training and technical assistance described in subparagraph (A) of this paragraph.".

Ante, p. 1749.

(b) Section 4 of the Act is further amended by adding after paragraph (3) the following new paragraph:

42 USC 5103.

"(4) Programs or projects related to child abuse and neglect assisted under part B of title IV of the Social Security Act shall

42 USC 620.

comply with the requirements set forth in clauses (B), (C), (E), (F), and (K) of paragraph (2).".

REGULATIONS AND GUIDELINES

42 USC 5103 note. Sec. 124. (a)(1) Not later than 60 days after the date of the enactment of this Act, the Secretary of Health and Human Services (hereinafter in this part referred to as the "Secretary") shall publish proposed regulations to implement the requirements of section 4(b)(2)(K) of the Act (as added by section 122(3) of this Act). Ante, p. 1752.

(2) Not later than 180 days after the date of the enactment of this Act and after completion of a process of not less than 60 days for notice and opportunity for public comment, the Secretary shall publish final regulations under this subsection.

(b)(1) Not later than 60 days after the date of the enactment of this Act, the Secretary shall publish interim model guidelines to encourage the establishment within health-care facilities of committees which would serve the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment (as that term is defined in clause (3) of section 3 of the Act (as added by section 121(3) of this Act)) from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions. Ante, p. 1752.

(2) Not later than 180 days after the date of the enactment of this Act and after completion of a period of not less than 60 days for notice and opportunity for public comment, the Secretary shall publish the model guidelines.

REPORT ON FINANCIAL RESOURCES

Study. 42 USC 5105. Sec. 125. The Secretary shall conduct a study to determine the most effective means of providing Federal financial support, other than the use of funds provided through the Social Security Act, for the provision of medical treatment, general care, and appropriate social services for disabled infants with life-threatening conditions. Not later than 270 days after the date of the enactment of this Act, the Secretary shall report the results of the study to the appropriate Committees of the Congress and shall include in the report such recommendations for legislation to provide such financial support as the Secretary considers appropriate.

IMPLEMENTATION REPORT

42 USC 5103 note. Sec. 126. Not later than October 1, 1987, the Secretary shall submit to the appropriate Committees of the Congress a detailed report on the implementation and the effects of the provisions of this part and the amendments made by it.

STATUTORY CONSTRUCTION

42 USC 5101 note. 29 USC 794. Sec. 127. (a) No provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973.

(b) No provision of this Act or any amendment made by this Act may be so construed as to authorize the Secretary or any other governmental entity to establish standards prescribing specific medical treatments for specific conditions, except to the extent that such standards are authorized by other laws.

Provisions held invalid.

(c) If the provisions of any part of this Act or any amendment made by this Act or the application thereof to any person or circumstances be held invalid, the provisions of the other parts and their application to other persons or circumstances shall not be affected thereby.

EFFECTIVE DATES

42 USC 5102 note.

Sec. 128. (a) Except as provided in subsection (b), the provisions of this part or any amendment made by this part shall be effective on the date of the enactment of this Act.

(b)(1) Except as provided in paragraph (2), the amendments made by sections 122 and 123(b) of this Act shall become effective one year after the date of such enactment.

Waiver.

Ante, p. 1752.

Ante, p. 1752.

(2) In the event that, prior to such effective date, funds have not been appropriated pursuant to section 5 of the Act (as amended by section 104 of this Act) for the purpose of grants under section 4(c)(1) of the Act (as added by section 123(a) of this Act), any State which has not met any requirement of section 4(b)(2)(K) of the Act (as added by section 122(3) of this Act) may be granted a waiver of such requirements for a period of not more than one year, if the Secretary finds that such State is making a good-faith effort to comply with such requirements.

TITLE II—AMENDMENTS TO THE CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT OF 1978

FINDINGS AND DECLARATION OF PURPOSE

Sec. 201. (a) The first sentence of section 201 of the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 (42 U.S.C. 5111) (hereinafter in this title referred to as "the Act") is amended—

(1) by inserting "the welfare of thousands of children in institutions and foster homes and disabled infants with life-threatening conditions may be in serious jeopardy and that some such children are in need of placement in permanent, adoptive homes; that" after "finds that"; and

(2) by inserting "have medically indicated treatment withheld from them, nor" after "should not".

(b) The second sentence of section 201 of the Act is amended—

(1) by inserting a comma and "including disabled infants with life-threatening conditions," after "special needs"; and

(2) by amending clause (2) to read as follows:

"(2) providing a mechanism for the Department of Health and Human Services to—

"(A) promote quality standards for adoption services, pre-placement, post-placement, and post-legal adoption counseling, and standards to protect the rights of children in need of adoption;

"(B) coordinate with other Federal departments and agencies, including the Bureau of the Census, to provide for a national adoption and foster care information data-gathering and analysis system; and

"(C) maintain a national adoption exchange to bring together children who would benefit by adoption and qualified prospective adoptive parents who are seeking such children."

MODEL ADOPTION LEGISLATION AND PROCEDURES

42 USC 5112

SEC. 202. (a) Section 202(a) of the Act is amended by striking out "Health, Education, and Welfare" and inserting in lieu thereof "Health and Human Services".

(b) Section 202(c) of the Act is amended by inserting at the end thereof the following new sentence: "The Secretary shall coordinate efforts to improve State legislation with national, State, and local child and family services organizations, including organizations representative of minorities and adoptive families.".

(c) Section 202 of the Act is further amended by inserting at the end thereof the following new subsection:

"(d) The Secretary shall review all model adoption legislation and procedures published under this section and propose such changes as are considered appropriate to facilitate adoption opportunities for disabled infants with life-threatening conditions.".

INFORMATION AND SERVICES

42 USC 5113

SEC. 203. (a) Section 203(a) of the Act is amended by striking out "Health, Education, and Welfare" and inserting in lieu thereof "Health and Human Services".

(b)(1) Section 203(a) of the Act is further amended by inserting before the period at the end thereof a comma and "including services to facilitate the adoption of children with special needs and particularly of disabled infants with life-threatening conditions and services to couples considering adoption of children with special needs".

(c)(1) Section 203(b) of the Act is amended by striking out in the matter preceding clause (1) "subsection (a) of this section" and inserting in lieu thereof "this title".

(2) Section 203(b)(1) of the Act is amended to read as follows:

"(1) provide (after consultation with other appropriate Federal departments and agencies, including the Bureau of the Census and appropriate State and local agencies) for the establishment and operation of a Federal adoption and foster care data-gathering and analysis system;".

(3) Section 203(b) of the Act is further amended—

(A) by striking out "parent groups" in clause (4) and inserting in lieu thereof "adoptive family groups and minority groups";

(B) by striking out "and" at the end of clause (4);

(C) by redesignating clause (5) as clause (7) and by inserting immediately after clause (4) the following new clauses:

"(5) encourage involvement of corporations and small businesses in supporting adoption as a positive family-strengthening option, including the establishment of adoption benefit programs for employees who adopt children;

"(6) continue to study the nature, scope, and effects of the placement of children in adoptive homes (not including the homes of stepparents or relatives of the child in question) by persons or agencies which are not licensed by or subject to regulation by any governmental entity; and"; and

(D) by striking out "Health, Education, and Welfare" and inserting in lieu thereof "Health and Human Services" in clause (7) (as redesignated by clause (C) of this paragraph).

AUTHORIZATION OF APPROPRIATIONS

42 USC 5115.

Sec. 204. Section 205 of the Act is amended by striking out "and" fter "1978," and by inserting a comma and "and $5,000,000 for each f the fiscal years 1984, 1985, 1986, and 1987," after "fiscal years".

Appendix J

Child Abuse Amendments Final Rule

federal register

Monday
April 15, 1985

Part VI

Department of Health and Human Services

Office of Human Development Services

45 CFR Part 1340

Child Abuse and Neglect Prevention and Treatment Program; Final Rule

Model Guidelines for Health Care Providers To Establish Infant Care Review Committees; Notice

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Human Development Services

45 CFR Part 1340

Child Abuse and Neglect Prevention and Treatment Program

AGENCY: Office of Human Development Services, HHS.

ACTION: Final rule.

SUMMARY: This rule contains a new basic State grant requirement to implement the Child Abuse Amendments of 1984 (Pub. L. 98–457). As a condition of receiving State grants under the Child Abuse Prevention and Treatment Act, States must establish programs and/or procedures within the State's child protective service system to respond to reports of medical neglect, including reports of the withholding of medically indicated treatment for disabled infants with life-threatening conditions.

Other changes in regulations required by these Amendments will be published as a separate NPRM at a later date.

DATES: This rule is effective May 15, 1985. However, as specified in Pub. L. 98–457 and the rule, operative requirements become effective October 9, 1985.

FOR FURTHER INFORMATION CONTACT: Jay Olson, (202) 245–2859.

SUPPLEMENTARY INFORMATION:

Program Description

The Child Abuse Prevention and Treatment Act (Public Law 92–247, 42 U.S.C. 5101, *et seq.*) was signed into law in 1974. It established in the Department of the National Center on Child Abuse and Neglect. The National Center is located organizationally within the Children's Bureau of the Administration for Children, Youth and Families in the Office of Human Development Services.

Under this Act, the National Center carries out the following responsibilities:

- Makes grants to States to implement State child abuse and neglect prevention and treatment programs.
- Funds public or nonprofit private organizations to carry out research, demonstration, and service improvement programs and projects designed to prevent, identify and treat child abuse and neglect.
- Collects, analyzes, and disseminates information, e.g., compiles and disseminates training materials, prepares an annual summary of recent and on-going research on child abuse and neglect, and maintains an information clearinghouse.
- Assists States and communities in implementing child abuse and neglect programs.
- Coordinates Federal programs and activities, in part through the Advisory Board on Child Abuse and Neglect.

The Act has been extended and amended several times since its passage. Regulations for the State grant and discretionary fund programs are found at 45 CFR Part 1340; the most recent revisions were published on January 26, 1983 (48 FR 3698). The fifty States, the District of Columbia, Puerto Rico, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, American Samoa, and the Trust Territory of the Pacific Islands are eligible to apply for State grants. Fifty-one of the fifty-seven eligible jurisdictions meet the requirements of the Act and the regulations and currently receive State grant funds. We will refer to these jurisdictions as "States" in this preamble discussion.

State Child Protective Service System

Funds from the State grant program are used to support the activities of the State Child Protective Service (CPS) system. State CPS agencies are the agencies designated in the State to respond to reports of child abuse and neglect. (All States have a CPS system and CPS agency whether they receive State grant funds under the Act or not.)

The CPS agency responds to reports of abuse and/or neglect, investigates, refers situations to law enforcement officials as appropriate, and provides treatment and services. The focus of the agency's efforts is on the family—to protect the child, preserve the home, prevent separation of the child from the family if at all possible, prevent further abuse or neglect, and alleviate or correct the factors leading to the report. The agency generally regards its contact with the family as a demonstration of community concern and evidence of a desire to be of help to both parents and children.

Anyone in a State may report known or suspected abuse and neglect. Local (city, county) telephone numbers for reporting are found in local telephone directories. States that have a Statewide 24-hour hot line typically give that number wide publicity. The list of CPS agency contacts in the NPRM was provided for general information purposes regarding the overall child protective service system, not for reporting specific instances of abuse or neglect.

Investigations, services, and other activities may be provided by CPS agency staff, by law enforcement agencies, by multidisciplinary teams (many of which are located in major hospitals), and by utilizing the services of other public and voluntary agencies in the community. Most CPS workers have specialized training, and multidisciplinary fact-finding teams often have some expertise in medicine, law and law enforcement, as well as in social work.

Notice of Proposed Rulemaking

On December 10, 1984, the Department published a Notice of Proposed Rulemaking (NPRM) (49 FR 48160) to implement a major new requirement in Pub. L. 98–457, the Child Abuse Amendments of 1984. This requirement, applicable to CPS agencies, is found in a new clause (K) in section 4(b)(2) of the Child Abuse Prevention and Treatment Act. It mandates that, in order to qualify for basic State grants under the Act, States must, by October 9, 1985 (within one year of enactment), have programs or procedures or both in place within the State's CPS system for the purpose of responding to reports of medical neglect, including instances of the withholding of medically indicated treatment (including appropriate nutrition, hydration and medication) from disabled infants with life-threatening conditions.

A definition of "withholding of medically indicated treatment" is given in section 3 of the Act and means the failure to respond to an infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions. Exceptions to the requirement to provide treatment (but not the requirement to provide appropriate nutrition, hydration, and medication) may be made only in cases in which:

(1) The infant is chronically and irreversibly comatose; or

(2) The provision of such treatment would merely prolong dying or not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or

(3) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

The Amendments also required the Department to publish interim model guidelines to encourage hospitals to establish committees to educate hospital personnel and families of disabled infants with life-threatening conditions, recommend institutional policies and guidelines concerning withholding of medically indicated treatment from such infants, and offer counsel and review in cases involving such disabled infants. Interim Model Guidelines were also published on December 10, 1984 (49 FR 48170).

We received more than 116,000 letters in response to the NPRM and the Interim Model Guidelines from a wide range of associations and individuals. The overwhelming majority of these comments expressed general support for the regulation. Many letters strongly endorsed the requirement that all disabled infants, regardless of their condition, receive appropriate nutrition and hydration, and the Department's interpretation that the law did not permit life and death treatment decisions to be made on the basis of subjective opinions regarding the future "quality of life" of a retarded or disabled person. Many of these commenters recommended the addition of more specific requirements they believed would more effectively protect disabled infants.

A number of commenters disapproved of the proposed rule. Some of them objected to any governmental action that they believed interfered with an individual's right to make personal decisions in this matter. Some commenters urged deletion of specific provisions of the proposed rule they believed were excessive or distorted the intent of Congress. Frequently identified in this connection were the clarifying definitions the Department proposed to support the basic statutory definition.

In addition, during the comment period, we met with representatives of a number of right-to-life, disability rights and medical organizations. A summary of the issues discussed and recommendations made at these meetings is included in the Department's public comment record.

Summary of the Final Rule

In the NPRM, the Department sought to adhere closely to the letter and spirit of the legislation. As noted at that time, this legislation was the product of an extraordinary effort on the part of several Senators and Congressmen and representatives of a wide range of medical, right-to-life and disability organizations to forge a substantial consensus on an effective and workable program to assure the provision of appropriate medical care to disabled infants. It was and continues to be of great importance to the Department to preserve and advance this consensus in order to most effectively implement this program.

It is clear that the legislation represented a careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable governmental intervention into the practice of medicine and parental responsibilities. In the NPRM, the Department's principal objective was to replicate this careful balance achieved in the legislation. Commenters on the NPRM gave the Department "mixed reviews" on how well this objective was accomplished.

Of special significance to the Department were the more than 115,000 letters from concerned citizens who strongly endorsed the compelling objective of assuring the provision of medically indicated treatment to disabled infants with life-threatening conditions. This was an overwhelming outpouring of letters from concerned citizens from all walks of life which significantly contributed to and reinforced the Department's commitment to develop an effective and workable regulation. Several major themes clearly emerged from this extraordinary volume of comments.

First, many of these commenters urged continued emphasis on the basic principle inherent in the statute that medical treatment decisions are not to be made on the basis of subjective opinions about the future "quality of life" of a retarded or disabled person. Many of these comments included personal and positive experiences and anecdotes relating to raising, being raised with, adopting, working with, or teaching disabled individuals. Some of these comments included photographs of natural or adopted disabled children or family members.

Second, these commenters urged adoption of requirements for child protective services agencies to implement program and/or procedures to fully effectuate the compelling statutory purpose. Suggestions were made for additional procedures dealing with access to medical records and the opportunity to obtain an independent medical examination, when necessary.

Third, many commenters strongly endorsed the Department's interpretations of key terms included in the basic statutory definition on the grounds that these clarifications were proper and important supplements to the statutory definition.

The Department also received a number of comments from medical associations whose support was essential to accomplishing the legislative compromise who argued that the careful balance evident in the statute was distorted by inclusion in the proposed rule of an inflexible catalog of binding definitions that counterproductively constrained the ability of reasonable medical judgment to react thoughtfully to the myriad of real-life problems in intensive care nurseries. These commenters made clear that their support for the legislation was based on inclusion in the compromise of deference to reasonable medical judgment, and that this element was insufficiently reflected in the proposed rule to allow their continued support.

In addition to the large number of comment letters we received, also noteworthy was a letter to Secretary Heckler from the six principal sponsors of the "compromise amendment" that became the provisions of the Child Abuse Amendments of 1984 dealing with services and treatment for disabled infants. This letter from Senators Hatch, Denton, Cranston, Nickles, Dodd and Kassebaum is especially important in reflecting the spirit of the extraordinary consensus reached through what the Senators referred to as the "painstaking negotiations" involving the diverse coalition.

The principal sponsors made several significant points. First, they noted that each word of the statutory definition "was chosen with utmost care" and indicated they were aware that the Department received numerous comments asking that the clarifying definitions be deleted. Although the principal sponsors did not specifically endorse these recommendations, they urged that they be given "every consideration" to ensure that the final rule is crafted with the same degree of care as was the statutory definition.

Second, the principal sponsors strongly urged that the word "imminent" not be used to characterize the proximity in time at which death is anticipated regardless of treatment in the context of situations in which treatment (other than nutrition, hydration, and medication) need not be provided. They stated:

> In the negotiations leading to the final language, there was much discussion about whether or not to include the word "imminent" in the statutory definition. It became apparent that "imminent" would create undue confusion both because it was ambiguous and because the expected time of death cannot be predicted with precision. A decision was made, therefore, not to include "imminent", and we urge that it be dropped in the regulations as well. Should the law in its present form prove ineffective, or harmful to infant care, we will seek appropriate legislative remedies

Third, they urged avoidance of the use of examples of specific medical conditions in a way that would be interpreted as "establishing federally-prescribed medical standards for approved treatment for specific cases."

Fourth, the principal sponsors urged clarifications concerning references to Infant Care Review Committees to "specifically make clear that the use of such committees is voluntary."

Finally, they recommended that the "existing cooperative relationship between state child protective services agencies and hospitals" be advanced by providing that the names, telephone numbers and titles of designated persons in the hospital be made known to the appropriate hospital staff and agency staff.

The Department has considered carefully the recommendations of the many commenters and the principal sponsors. This consideration has led to a number of revisions to the rule. These revisions reflect a reaffirmation of the Department's objective of replicating the careful balance accomplished in the legislation by the six principal sponsors, the diverse coalition of medical, pro-life and disability organizations, and the Congress as a whole between the need for an effective program and the need to prevent unreasonable governmental intervention.

This balancing effort has produced a number of decisions. First, the Department has adopted a recommendation that appeared to be unanimous among all of the medical associations whose endorsement was central to accomplishing the legislative compromise to delete the proposed rule's clarifying definitions from the text of the final rule. Only two of the clarifying definitions, those that appeared in the Conference Committee Report, have been adopted in the final rule.

Second, because the Department continues to believe that guidance relating to interpretations of key terms used in the statutory definition of "withholding of medically indicated treatment" will aid in effective implementation of the statute (a belief shared by many commenters), the Department is stating clearly its interpretative guidelines regarding these key terms in an appendix to the final rule. This appendix will be codified as an appendix to 45 CFR Part 1340. In publishing these interpretative guidelines, the Department is not seeking to establish them as binding rules of law, nor to prejudge the exercise of reasonable medical judgment in responding to specific circumstances. Rather, this guidance is intended to assist in interpreting the statutory definition so that it may be effectively and rationally applied in specific cases so as to fully effectuate the statutory purpose of protecting disabled infants.

The third conclusion arising from this balancing effort is that the Department's interpretative guidelines included in the appendix to the final rule continue to make clear the Department's interpretation that the statute unambiguously directs reasonable medical judgments to matters regarding treatment (including appropriate nutrition, hydration and medication) which "will be most likely to be effective in ameliorating or correcting" all of the infant's life-threatening conditions, and that it does not sanction decisions based on subjective opinions about the future "quality of life" of a retarded or disabled person.

Fourth, in offering the interpretative guidelines in the appendix and in providing the rationale for the interpretations, the Department will avoid using examples of specific diagnoses to elaborate on meaning. This action should avoid the essential thrust of the interpretative guidelines being lost amidst uncertainty regarding how the addition or subtraction of particular complications or medical nuances might affect the examples. It should also allay concerns that the proposed rule presented what some commenters referred to as a "cookbook approach" to the practice of medicine.

Fifth, the term "imminent" that appeared in the proposed rule in connection with the prognosis that no treatment will prevent death of the infant has been deleted from the Department's interpretative guidelines that appear in the appendix. This revision will assure no deviation from the resolution of a matter specifically decided during the legislative negotiations. The guidelines, however, continue to make clear that treatment may not be withheld solely due to a distant prognosis of death.

Sixth, the Department has adopted the recommendations of many commenters that specific provisions of the rule address child protective services agency procedures to gain access to medical records when necessary, to obtain a court order for an independent medical examination when necessary, and to identify the designated hospital liaison persons to facilitate coordination with the child protective services agency.

The Department believes these revisions will ensure that the final rule reaffirms the legislative commitment to a program that deserves the support of a diverse coalition of associations and individuals. The section-by-section analysis in this preamble and the appendix to the final rule describe these revisions in greater detail, and discuss the significant comments received by the Department.

In addition, Model Guidelines for Health Care Providers to Establish Infant Care Review Committees are being published elsewhere in today's Federal Register, along with a discussion of the comments received.

Section-by-Section Discussion of the Comments

Before beginning the section by section discussion, we would like to respond to some basic questions and concerns expressed in the comment letters. Many commenters asked for clarification regarding who was the decision maker for the treatment of the infant, what was the focus of the CPS agency's concern, and exactly how these new requirements should be implemented.

In the NPRM, we described the new requirements in the context of a discussion of the role and function of the CPS system and its focus on the family. The decision to provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian. Parents are the decision makers concerning treatment for their disabled infant, based on the advice and reasonable medical judgment of their physician (or physicians). The counsel of an Infant Care Review Committee (ICRC) might also be sought, if available. Therefore, if a report is made to the CPS agency, either by a physician, a nurse, the person designated by the hospital/health care facility, or by any other person, the focus of the CPS agency's work will be, as it is in responding to other reports of child abuse or neglect, to protect the child and assist the family.

We want to emphasize that it is not the CPS agency or the ICRC or similar committee that makes the decision regarding the care of and treatment for the child. This is the parents' right and responsibility. Nor is the aim of the statute, regulations, and the child abuse program to regulate health care. The parents' role as decision maker must be respected and supported unless they choose a course of action inconsistent with applicable standards established by law. Where hospitals have an ICRC or similar committee and the review and counsel of the ICRC is sought, it is the role of the ICRC to review the case, provide additional information as needed to insure fully informed decision-making, particularly in difficult cases, and recommend that the hospital seek CPS agency involvement when necessary to assure protection for the infant and compliance with applicable legal standards.

With respect to reporting, we also want to emphasize that anyone at any time may report cases of known or suspected abuse or neglect to the local CPS agency. Reporting may be required of certain categories of persons by State law, but reporting is not limited to physicians, ICRC members, designated individuals in health care facilities, or any others. We hope this statement will reassure and resolve the concerns of many commenters who appeared to believe that reports could come only from individuals designated by the hospital or health care facility, or other hospital personnel, e.g., an ICRC member.

With respect to how the new requirements are to be carried out, several key points clearly emerge from the statute and the legislative history.

First, procedural requirements should build upon existing mechanisms at the state level, rather than creating a new system and a new bureaucracy to respond to reports of known or suspected instances of the withholding or medically indicated treatment from infants with life-threatening conditions.

Second, in responding to such reports, CPS agencies are to coordinate and consult with individuals designated by and within the hospital in order to avoid unnecessary disruption of ongoing hospital activities.

Third, the legislation was not intended to require child protection workers to practice medicine or second guess reasonable medical judgments. Rather, Congress intended that the child protective agency respond to reports of suspected medical neglect under procedures designed to ascertain whether any decision to withhold treatment was based on reasonable medical judgment consistent with the definition of "withholding of medically indicated treatment."

Finally, if the CPS agency determines there is a withholding of medically indicated treatment from a disabled infant with a life threatening condition(s), the agency is to pursue the appropriate legal remedies provided by State law to prevent the withholding.

The Department is not prescribing any particular process or investigative steps that must be followed by the CPS agency in every case. Under the Act and existing regulations, basic standards are established but detailed procedures are not dictated. Each CPS agency has the flexibility to work out its own internal investigative procedures and develop mechanisms to provide for coordination and consultation with local health care facilities and other organizations and agencies. Therefore, this rule does not require the CPS agency to consult with State or local agencies representing the disabled or any other organizations or agencies in the development of their programs and procedures or publish the procedures for public comment.

Section 1340.14 Eligibility requirements.

We have made a technical change in the lead-in sentence in § 1340.14 to include the eligibility requirements in § 1340.15.

Section 1340.15(a) Purpose.

In response to several comments, we have added, for specificity, the words "with life-threatening conditions" to the end of the sentence in paragraph (a).

Section 1340.15(b) Definitions.

1. *The term "medical neglect"—§ 1340.15(b)(1).* Paragraph (b)(1) defines the term "medical neglect," used in the final rule. This term is also used in the new section 4(b)(2)(K) of the Act, which requires states to have programs and/or procedures "for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions)." The term "medical neglect" is not defined in the statute, nor in the existing regulation. However, section 3 of the Act, prior to the 1984 amendments, defined "child abuse and neglect" to include "negligent treatment or maltreatment," and the existing regulation (§ 1340.2(d)(3)(i)) defines this latter term to include the "failure to provide adequate food, clothing, shelter, or medical care." The new law and its legislative history make clear that Congress understood and intended that "medical neglect" is a form of "child abuse and neglect" within the meaning of the Act and the present regulations, and that the "withholding of medically indicated treatment from disabled infants with life-threatening conditions" is a form of medical neglect.

Because of these factors, paragraph (b)(1) simply "closes the loop" by defining "medical neglect" as the failure to provide adequate medical care, and by stating that medical neglect includes, but is not limited to, the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

2. *The term "withholding of medically indicated treatment"—§ 1340.15(b)(2).* Paragraph (b)(2) of the final rule defines the term "withholding of medically indicated treatment" with a definition identical to that which appears in section 3(3) of the Act (as amended by section 121(3) of the Child Abuse Amendments of 1984).

As clearly documented in the legislative history of the Child Abuse Amendments of 1984, this statutory definition was the central element of what was repeatedly referred to as the "compromise amendment" that emerged from lengthy negotiations among senators and representatives of medical, disability and right-to-life organizations. *See* H. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 40 (1984); 130 Cong. Rec., S. 9312 (Daily Ed., July 26, 1984) (remarks of Sen. Denton). The essence of this compromise was to reach a careful balance between the need for meaningful protections of the rights of disabled infants to receive appropriate medical care with the need to avoid unreasonable governmental intervention into the practice of medicine or parental responsibilities.

In the proposed rule, the Department proposed a number of clarifying definitions of terms used in the statutory definition. Because the Department was not represented in the lengthy negotiations that produced the compromise amendment, the Department specifically solicited comments on these clarifying definitions. Many were received.

A significant number of comments from medical associations that were major participants in the Congressional negotiations argued that the careful balance evident in the compromise amendment they endorsed was insufficiently reflected in the proposed rule. These commenters uniformly argued that the clarifying definitions, taken as a whole, could be construed so as to have the effect of distorting the legislative compromise, which, they said, did not contemplate regulatory elaborations of the definition.

It was not the Department's intent in the proposed rule to deviate from the letter or the spirit of the compromise amendment. HHS believes it is important to the successful implementation of this law to seek to maintain the statute's careful balance and to preserve and advance the substantial consensus that joined to support the legislative compromise. The Department also continues to believe that successful implementation of this statute will be advanced by offering guidance that will assist in understanding the statutory definition. Thus, the clarifying definitions have been deleted from the text of the regulation, except for the two that were adopted by Congress in the Conference

Committee Report. However, as noted above, the Department's interpretations of these terms are set forth and explained in the appendix to the final rule, which will become an appendix to this rule in the Code of Federal Regulations. The Department believes that these interpretative guidelines can and should be referred to by interested parties in understanding, interpreting and applying the statutory definition. Changing the Department's interpretations from regulatory definitions to interpretative guidelines should allay concerns that the proposed rule could have been construed so as to distort the Congressional compromise by establishing binding rules of law that may compound rather than resolve the myriad of real-life problems in intensive care nurseries, while still giving all parties the benefits of very relevant interpretations of the statute by the agency charged with its implementation.

3. The term "infant"—§ 1340.15(b)(3)(i). The Conference Committee Report included a definition of "infant," which has been adopted in very similar terms in paragraph (b)(3)(i). The apparent reason Congress defined the term is that "infant" does not have a single, commonly accepted meaning. *Dorland's Medical Dictionary*, for example, states that infancy is frequently regarded as extending "to the time of assumption of erect posture (12 to 14 months)"; but is also sometimes regarded "to extend to the end of the first 24 months." *Dorland's Illustrated Medical Dictionary* (26th Edition, 1981), p. 663.

The Conference Committee made clear that its principal focus was on infants less than one year of age. However, the Committee made several other points obviously designed to ensure that the one-year definition would not be applied so arbitrarily and rigidly that infants over one year old would not receive appropriate attention from child protective services systems. Thus, the Conference Committee stated that the principal focus on infants less than one year old did not imply "that treatment should be changed or discontinued when an infant reaches one year of age," nor was it intended "to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age." H. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 41 (1984).

Thus, as a general rule, issues of medical treatment for infants over one year of age are to be considered under the less precisely defined, but clearly applicable, standards of "medical neglect." Issues of medical treatment for disabled infants under one year of age with life-threatening conditions must be considered under the more precisely defined standards of the definition of "withholding of medically indicated treatment."

One more factor was added by the Conference Committee. For certain infants over one year of age, the Conference Committee believed the more precisely defined standards of the definition of "withholding of medically-indicated treatment" might be more appropriate to use in considering the question of medical treatment than the more general standards of "medical neglect." Thus, the Conference Committee stated that the more precisely defined standards "may" be applied to those infants over one year of age "who have been continuously hospitalized since birth, who were born extremely prematurely or who have long-term disabilities." *Id.* The apparent Congressional intent is to recognize that these three categories of infants, although over one year of age, share important characteristics with those infants under one year of age who are the principal focus of the statutory provision.

The Department has incorporated these points into the definition of "infant." On the last point discussed, the definition has been revised somewhat from that which appeared in the proposed rule. The proposed rule stated that the term "infant" always included the three categories of infants over one year of age described above, or in other words, that the standards of the more precise definition of "withholding of medically indicated treatment" would always apply to the consideration of medical neglect of these infants. In response to comments that this deviated from the "may include" standard of the Conference Committee, the provision has been revised to assure consistency with Congressional intent. The Department interprets the "may include" language relating to these categories of infants over one year of age as indicating Congress' intent that the standards of the more precise definition should be consulted thoroughly in the evaluation of any issue of medical neglect regarding these infants. Thorough consideration of these standards will permit an informed judgment on whether these standards in fact constitute the most appropriate basis for evaluation of the medical neglect issue.

A number of other comments were made regarding the definition of "infant," particularly regarding inclusion in the term of the three categories of infants over one year of age. Some commenters suggested that this provision be expanded, such as to include all children. Other commenters argued that the provision should be revised to prevent the inclusion of adults who, for example, have had a long-term disability since birth. Other commenters suggested specific inclusion of infants born alive after attempted abortions.

The definition of the term "infant" has not been revised in response to these suggestions. As explained above, the Congressional intent was that the standards of "medical neglect," rather than the more precisely articulated standards of the definition of "withholding of medically indicated treatment" apply to older children. The definition does make clear, however, that this shall not be construed to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age.

In addition, no revision is necessary to clarify that "infant" does not include older children and adults. The potential appropriateness of applying the more precisely stated standards of the definition of "withholding of medically indicated treatment" to certain infants over one year of age is still stated, as it was in the proposed rule and in the Conference Report, in terms of *infants* over one year of age. Older children and adults are not "infants over one year of age."

Finally, no change is necessary to clarify that infancy begins at the point of live birth, regardless of the circumstances of the live birth.

4. The term "reasonable medical judgment"—§ 1340.15(b)(3)(ii). Clause (b)(3)(ii) defines the term "reasonable medical judgment" used in the statutory definition of "withholding of medically indicated treatment." It is identical to the definition contained in the Conference Committee Report, H. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 41 (1984).

Section 1340.15(c) Eligibility

We have made three additions to paragraph (c). First, many commenters believed that the name, title and telephone number of the person designated by the health care facility should be widely publicized, e.g., made known not only to the CPS agency but to all employees of the facility, to all parents of disabled children being treated in the facility, and to the community at large. We agree that in order for the CPS agency to carry out its responsibilities in paragraph (c)(2) of this section for coordination and consultation with and receipt of prompt notification from individuals designated by and within appropriate health care facilities, it must at least know the name, title and telephone number of the designated person(s). Therefore, we have added a new paragraph (c)(3) to require that the CPS agency promptly contact each health care facility to obtain the name, title, and telephone number of the individual(s) designated by the facility as responsible for coordinating and consulting with and promptly notifying the State CPS agency of cases of known or suspected medical neglect. We have also required that, at least annually, this information be verified for accuracy.

With respect to the recommendation that we require hospitals to publicize the identification of the designated contact person with the hospital, this is not mandated because matters relating to the internal affairs of hospitals are beyond the scope of this regulation. However, we strongly encourage hospitals to make this information known within the facility as a way of assuring the protection of infants.

Essentially, paragraphs (c)(2)(i) and (ii) require the development of a coordination and communications system whose purpose is to assure that reports of suspected medical neglect are made at optimum speed. This communications system should operate whether the reports are made by the designated individual(s) or by any other person, and whether they are reports requesting CPS agency intervention and legal protection of an infant or reports requesting an initial CPS agency investigation. Under all these circumstances, rapid communication is of the utmost importance. Many letters from health care facilities indicated their plans that the designated individual will also assist the CPS agency staff and/or agency medical consultant in investigating a report and in facilitating other protective actions as needed.

We have not accepted the recommendation that the individual designated by the health care facility must, in all cases, be a member of the ICRC in order to assure that the CPS agency will receive reports of medical neglect. We do not have statutory authority to require ICRCs or similar committees and must adhere to the statutory requirement that the selection of the designated individual be made by the health care facility.

We have not accepted the recommendation that the name, title, and telephone number of persons designated by health care facilities be published annually in the newspaper of general circulation in the geographic area served by the facility. Commenters appeared to believe that this would enable the public to report suspected instances of medical neglect to the hospital and the hospital could report it to the CPS agency. As we have stated above, anyone may report such cases directly to the CPS agency.

Second, we agree with the many commenters who recommended that the State CPS agency may, in some cases, need access to an infant's medical records and an opportunity to conduct an independent medical examination of the infant. We have added language to paragraph (c)(4) to require that as a part of the development of programs and/or procedures required in paragraph (c), the State child protective system must specify the procedures to be followed, consistent with State law, to carry out these actions. Paragraph (c)(4)(i) requires that procedures be developed, consistent with State law, to obtain access to medical records and/or other pertinent information when such access is necessary to assure an appropriate investigation of a report of medical neglect; paragraph (c)(4)(ii) requires that procedures be developed, consistent with State law, to obtain a court order for an independent medical examination of the infant, or otherwise effect such as examination in accordance with the process established under State law, when necessary to assure an appropriate resolution of a report of medical neglect.

These two additions elaborate on the requirement included in paragraph (3) of the proposed rule that the State's programs and/or procedures must conform with the requirements of section 4(b)(2) of the Act and § 1340.14 of the existing regulations. The Act and existing regulations require States to have procedures for adequate investigations and the provision of protective services. Existing regulations also make reference to medical examinations, the provisions of medical services, and related actions. See section 4(b)(2)(C) of the Act and § 1340.14(d), (f), and (h). These additions to paragraph (c)(4) of the final rule clarify that, in connection with this conformity requirement, the State's programs and/or procedures must make provision, consistent with State laws, for access to medical records and medical examinations when necessary. Although these actions will not be needed in every investigation of reported medical neglect, the specific identification of these procedures for use by agency staff increases the protections for disabled infants.

We have not adopted other recommendations for specific State agency investigative procedures or requirements, e.g., that the CPS agency must obtain a full consultation with the attending physicians and consultants and with an independent medical consultant prior to taking any enforcement action. We believe that any such special limitations would be inconsistent with Congressional intent that existing procedures and methods be utilized.

Other comments regarding § 1340.15(c) and our response are as follows:

Designation of the CPS Agency. A few commenters stated that it was not clear whether the intent of the regulations was to expand existing CPS agency programs to include the population defined or whether a parallel system was contemplated. One national professional social service organization recommended that States be mandated to establish an agency or agencies responsible for responding to reports of medical neglect of disabled infants and observed that child welfare agencies traditionally have given lower priority to handicapped children than mental health or mental retardation agencies, for example.

We believe it is the clear intent of Congress that States utilize their existing child protective service system to carry out this new responsibility. As indicated in the legislative history, however, States have the flexibility to determine the specific agency or agencies within their child protective service system to exercise the authority to institute legal proceedings on behalf of the disabled infants referenced in new clause (K) of section 4(b)(2) of the Act. (See H. Conf. Rept. 98–1038, pp 41–2.)

Requirement for a new State statutory definition. One commenter suggested that States be required to amend their State statutes to include the definition of "withholding of medically indicated treatment." Neither the statute nor the legislative history indicates that Congress intended that States enact this definition. Rather, the legislative history indicates Congress' understanding that States currently can receive reports concerning, and provide protection to, disabled infants with life-threatening conditions under present statutes and definitions. The documentation requirements in paragraph (d) are designed to be consistent with this understanding.

Funding. Several letters raised the matter of funding, not only for treatment costs of disabled infants but also for

CPS agency costs of additional staff, training, medical consultation, and development of procedures.

For FY 1985, Congress provided funds under the Act as follows: the basic State grant funds were increased from $7 million to $9 million and new funds totaling $3 million were appropriated specifically to assist States to implement provisions related to section 4(b)(2)(K). In addition, HDS will make funds available under section 4(c)(2) of the Act to enable States to obtain training and technical assistance to carry out section 4(b)(2)(K) requirements. HDS also plans to award approximately $2 million in "special grant" funds to assist States in implementing several priority child abuse prevention initiatives, including the provisions of section 4(b)(2)(K).

We do not have statutory authority and decline to require States to assume full financial responsibility for the maintenance and medical costs of all such disabled children.

Waiver of effective date. Paragraph (c)(4) of the NPRM (now paragraph (c)(5) of the final rule) stated that the eligibility requirements under § 1340.15 are effective October 9, 1985, the effective date established in the Child Abuse Amendments of 1984. One State social service agency questioned whether it was possible to meet the requirements by October 9, 1985 and asked about the availability of a waiver. The Act, however, does not permit the new waiver provision in section 4(b)(3) of the Act to apply to the section 4(b)(2)(K) requirements.

It should be noted that, consistent with standard agency practice, the final rule becomes effective 30 days from the date of publication in the Federal Register. However, as specified in paragraph (c)(5), the actual effective date for State agency programs and/or procedures to be in place is October 9, 1985. See section 4(b)(2)(K) of the Act and section 128 of Pub. L. 98-457.

Increased Federal involvement and enforcement. Because the Act so clearly places the responsibility for implementation on State CPS agencies, the Department does not see a need to establish a Federal hot-line for reporting suspected instances of medical neglect as requested by some commenters. Such a federal reporting system would not be the most effective in assuring the most prompt reporting to State or local CPS agencies. Again, we urge that interested persons note the telephone number of the local agency that receives reports of abuse and neglect.

Implementation. Section 4(c)(2)(A)(ii) of the Act requires the Department to provide for the establishment and operation of national and regional information and resource clearinghouses for the purpose of providing the most current and complete information regarding medical treatment procedures and resources and community resources for the provision of services and treatment for disabled infants with life-threatening conditions. Many letters expressed strong support for these and other educational efforts that may be undertaken by the Department, particularly in the field of neonatology. Currently, we are in the process of determining how best to implement these clearinghouse requirements. Once they are in operation, we will inform the health care community, the State CPS agencies, and the national disability and right to life associations of procedures for accessing the information. Therefore, we do not believe it is necessary or appropriate to require that CPS agencies be responsible for informing health care facilities of the clearinghouses and access procedures. We also decline to require that the CPS agency consult with the clearinghouse) (or the ICRC or similar committee consult with the clearinghouse) in every CPS agency investigation or ICRC review. We believe that these decisions are best made based on the circumstances of each individual case.

We understand that in several States the CPS agency and State and local medical associations and other organizations have begun to work together to implement reporting, coordination, and procedural development requirements. As a point of information, the American Bar Association is preparing a series of suggested legal procedures for States, hospitals, physicians, and prosecutors that will assure that investigations and decisions regarding disabled infants will comport with State and Federal law. The results of this project, funded by the National Center on Child Abuse and Neglect, are expected in late summer.

Section 1340.15(d) Documentation.

Regarding suggestions to amend paragraph (d), several commenters recommended that each hospital or health care facility be required to provide the State CPS agency with a written copy of its internal procedures for responding to internal reports of possible withholding of medically indicated treatment, including procedures for review by ICRCs or similar committees. Other commenters recommended requiring documentation that the State CPS agency routinely review the procedures used by health care facilities to ensure that both hospital personnel and patient families are fully informed of the existence and functions of any ICRC or other relevant decision-making body established by or operating within the health care facility.

While we encourage hospitals and health care facilities to establish ICRCs, or similar committees, and necessary implementing policies and procedures, we do not believe it is appropriate to require CPS agency review of health care facility procedures or necessary as a documentation requirement. Regulation of internal management procedures of hospitals is not required in the Act, is beyond the scope of the State child protective service system, and thus, is not a proper matter to be dealt with in this rule. Another comment letter on the first point, however, suggested that useful training for CPS and hospital staff might include an introduction to the decision-making processes and procedures within each agency/organization.

Section 1340.15(e) Regulatory construction.

Paragraph (e) of the final rule sets forth two provisions regarding the impact of this section. Both of these provisions are based on similar provisions contained in section 127 of the Child Abuse Amendments of 1984.

Section 127(a) of the Amendments states:

> No provision of this Act or any amendment made by the Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973.

Section 504 of the Rehabilitation Act is the Federal law that prohibits discrimination on the basis of handicap in programs and activities that receive Federal financial assistance. The HHS implementing regulations for section 504 are at 45 CFR Part 84.

Consistent with the statutory provision, paragraph (e)(1) states that no provisions of this regulation will affect any right, protection, procedure or requirement of the HHS regulations implementing section 504, 45 CFR Part 84.

This reference to Part 84 includes 45 CFR 84.55 (49 FR 1622, January 12, 1984), which establishes certain procedures relating to health care for handicapped infants. This regulation is based on the Department's interpretation that under section 504 of the Rehabilitation Act of 1973, health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.

This regulation establishes certain procedural requirements and guidelines. First, it encourages hospitals to establish Infant Care Review Committees and provides a model committee. Second, it requires each State child protective services agency that receives Federal financial assistance to establish and maintain procedures to assure that the agency utilizes its full authority pursuant to State law to prevent instances of unlawful medical neglect of handicapped infants. Third, it establishes certain procedures relating to the Department's interpretation of its authority to conduct investigations of complaints of alleged discriminatory withholding of treatment from handicapped infants.

In June of 1984, a Federal court invalidated this regulation and enjoined further investigations of alleged discriminatory withholding of medical treatment from handicapped infants under section 504. *American Hospital Association* v. *Heckler*, et al., 585 F. Supp. 541 (S.D.N.Y.), *aff'd*, Nos. 84-6211, 84-6231 (2d Cir., Dec. 27, 1984), *petition for cert. filed* (Mar. 27, 1985). The Solicitor General, on behalf of the Department, has petitioned the Supreme Court to accept this case for decision.

Consistent with section 127(a) of the Child Abuse Amendments of 1984 and the clear legislative history establishing a Congressional "policy of neutrality" on this legal controversy concerning the applicability of section 504 to health care for handicapped infants, (see *Congressional Record*, Vol. 130, S-12392, daily edition September 28, 1984 (letter from Senators Hatch, Denton, Nickles, Kassebaum, Dodd, and Cranston)), paragraph (e) of this regulation makes clear that this regulation in no way affects the prior regulation under section 504.

The Department received a number of comments regarding this provision of the proposed rule. Some commenters argued that because of the enactment of the Child Abuse Amendments of 1984, HHS should discontinue its efforts to deal with the issue of medical care for disabled infants under the authority of section 504. Other commenters suggested that the Department take some action in the context of this regulation that would establish a direct interrelationship between 45 CFR 1340.15 and 45 CFR Part 84.

The Department believes that the efforts previously undertaken under the authority of section 504 were, and continue to be, necessary and appropriate, both as a matter of law and important national policy. There are substantial similarities between the section 504-based rule and the Child Abuse Amendments of 1984. Both seek to assure the provision of medically indicated treatment, and incorporate into this goal respect for reasonable medical judgment, exclusion of futile treatments, and the like. Both approaches encourage the formation by hospitals of Infant Care Review Committees. Both approaches also recognize the need for State child protective services agencies to have specific procedures in place to deal with this form of medical neglect.

The major difference between the section 504-based approach and that of the Child Abuse Amendments of 1984 is that the former is implemented and enforced directly by the Federal government, whereas the latter, within the framework of the Child Abuse Prevention and Treatment Act, relies on State implementation and enforcement regarding individual instances of child absue and neglect (which includes medical neglect, which, in turn, includes the withholding of medically indicated treatment from disabled infants with life threatening conditions). The section 504-based system, thus, is fully compatible with the Child Abuse Amendments of 1984 approach, but has the additional element of a compliance mechanism of direct Federal intervention as a "back-up" to the mechanisms of Infant Care Review Committees (where implemented) and child protective services systems.

The Department believes that the compatibility of these two authorities strongly suggests the utility of assuring, if both are operational, that they are fully coordinated. The Department's goal in pursuing, through litigation, reinstatement of the section 504-based authority, is to clear the way for action to forge such an effective interrelationship between the two authorities.

But the Department also believes that it would conflict with clearly stated Congressional intent to now undertake efforts to establish such an interrelationship in the context of this regulation. The legislative history of the Child Abuse Amendments clearly reflects a "policy of neutrality" concerning the section 504-based program. This final rule is fully in accord with this policy of neutrality. When the controversy regarding the section 504-based program is resolved in the context of the present litigation, the question of the most effective interrelationship between the two authorities will, if the Department's position prevails, then be addressed.

Other commenters questioned why the statutory formulation of disavowing any intent to "affect any right or protection" under section 504 was expanded in the proposed rule to "affect any right, protection, procedure, or requirement" under the section 504 regulations. The reason is simply that whereas the statute establishes broadly-worded rights and protections, the regulation, in addition to fleshing out those rights and protections, establishes enforceable procedures and requirements. Thus, the transition from the statutory "policy of neutrality" to the regulatory "policy of neutrality" gives rise to the inclusion of these regulatory procedures and requirements. For example, if 45 CFR 84.55 (the section 504-based regulation that established certain procedures relating to health care for handicapped infants, but was invalidated by court order) is reinstated through further litigation, the procedures and requirements included in that section will be back in full force, unaffected by anything in this final rule. (It will then be for the Department to decide whether any changes in § 84.55 should be made to establish the most effective interrelationship between the two authorities.) Nothing more or less is intended or effectuated by paragraph (e)(1).

Paragraph (e)(2) is a new provision; it did not appear in the proposed rule. Similar to paragraph (e)(1), paragraph (e)(2) adopts, for purposes of regulatory construction, a provision corresponding to the Act's statement of statutory construction. Section 127(b) of the 1984 Amendments states:

> No provision of this Act or any amendment made by this Act may be so construed as to authorize the Secretary or any other governmental entity to establish standards prescribing specific medical treatments for specific conditions, except to the extent that such standards are authorized by other laws.

In response to suggestions from commenters, paragraph (e)(2) adopts in the regulation the same rule of construction in identical operative terms.

Impact Analysis

A number of commenters raised questions about possible costs and related impacts of these rules. Most common was a concern that the definitions created by these rules might lead to large numbers of cases involving costly treatments. Others expressed concern as to who might pay for the costs of expensive treatment. A few pointed out that early treatment could avoid even more costly future treatment in some cases. And a number expressed concerns over administrative aspects of these rules, such as involvement of child abuse agencies or creation of infant care review committees, which might create substantial administrative or legal costs, including disruption of existing arrangements.

Our view was, and remains, that these rules are not likely to result in an "annual effect on the economy of $100 million or more", or a "significant economic impact on a substantial number" of health care providers, as provided in Executive Order 12291 and the Regulatory Flexibility Act, respectively. We have, as previously discussed, eliminated many of the definitions which gave rise to these concerns.

More importantly, the role of these rules in the larger context of medical care for infants is minor. Nonetheless, there are large costs involved in medical care of infants with life-threatening conditions and we agree that such costs are in the aggregate quite high. Our point was simply that the costs of a rule include only those costs which the rule itself causes, and aggressive and sometimes quite costly care for such infants is already an established and growing feature of the American health care system, quite apart from passage of the Child Abuse Amendments of 1984.

The Larger Context of Newborn Care

Early in this century, very large advances in public health measures and medical treatment led to significant reductions in infant mortality and a huge increase in life expectancy. In recent years such advances have continued. From 1970 to 1980, infant deaths per thousand live births dropped from 20 to 13. In the same period, fetal death rates dropped form 14 to 9 per 100,000 live births, and neonatal deaths from 15 to 8 per thousand live births. Similar reductions continue in the 1980's.

These recent advances reflect a variety of factors ranging from generally better nutrition, improved access to medical care both pre and post-partum, advances in diagnosis and treatment, new surgical techniques, and improved organization and management of infant care (as reflected in the creation of "tertiary care" hospital units specializing in intensive neonatal care). Many of these most recent advances do not involve saving the lives of normal infants brought to normal term—those infants were already surviving. Instead, we are now routinely saving infants who would surely have died even a decade ago.

Such improvements are costly. One recent study points out that the great majority of cases (80%) at a tertiary care center are relatively inexpensive (costing an average of $8,000) but that most of the rest cost $20,000 or more and some involve hospital costs in the hundreds of thousands of dollars. Cost of hospital treatment for all these infants averages over $20,000. Further, some of the infants who now survive will require costly services for the rest of their lives.

About 2½% of all births involve a significant physical defect of some kind. Most of these, however, are not life threatening and do not require immediate, major medical intervention. For example, club foot and cleft lip and palate are among the most common defects, as are a variety of heart defects. Children with birth defects affecting mental functions such as Down Syndrome or Spina Bifida, are much rarer. Indeed, the majority of the most expensive infant care cases come from the 40,000 infants born each year with birth weights of 1500 grams or less who are normal in other respects. In many cases their care will involve life and death decisions, and some fraction of these will pose ethical and medical dilemmas, such as whether a particular child can be treated effectively or without inhumane pain and suffering. The crucial point is that virtually all such infants now, and in the future will, receive "state of the art" medical care, often at great expense, quite irrespective of the new statutory provisions of this rule.

Similarly, the vast majority of these infants have their care paid for by private health insurance or, in a minority of cases, by the Medicaid program.

The Maternal and Child Health Block Grant and other State funds can also pay for care, at State discretion. Some small fraction of parents do not have sufficient insurance coverage, or will face subsequent costs not covered by any medical insurance. Again, these problems exist quite irrespective of the new statutory provision or this rule. (In response to a Congressional mandate, the Department is preparing a special report dealing with financial resources for care of disabled infants with life-threatening conditions.)

Overall Effects of the Statute and Rule

Against this backdrop, the statute and this rule can readily be placed in perspective. In some unknown but very small fraction of infants, medically indicated treatment may have been or would have been withheld but for the response to the "Baby Doe" cases (including not only the law and this rule, but also public awareness and prior rules). However, the great majority of expensive interventions would occur—and are already occurring at annual costs in the range of several billion dollars—regardless of this change.

A considerable number of examples were used by commenters asserting that the statute or the rule would force inappropriate medical intervention, would force unnecessary and expensive evaluation by expert physicians and referral to expert facilities (e.g., neonatal tertiary care centers), or even inappropriate care for infants who were dying and for whom attempted treatment would be inhumane. Our response to these allegations is found elsewhere in this preamble. However, even if these assertions had all been correct, the examples involved rare conditions for which the potentially affected population is extremely small. Regardless, the changes made in this final rule should eliminate any doubt on this point.

Other commenters argued that the statute or rule would force use of truly experimental research procedures. Nothing in the statute or rule forces use of experimental procedures. To the contrary, medical ethics, federal regulations, and many State laws require that patients (or their parents) provide "informed consent" based on free choice and without coercion when physicians propose human experimentation. These rules do not require such experimentation.

Some commenters raised the possibility that the potential for legal action would lead to inappropriate "defensive" practices such as treatment of infants who were in fact dying and for whom attempted treatment would be inhumane. Such a possibility clearly exists, simply because human decisions are never perfect. Moreover, prudent persons would take care not to expose themselves to possible governmental or legal challenge and one way to do so is to pursue treatment in cases right on the "margin." However, substantial protection against such challenges arises from the deference provided reasonable medical judgment by the statute: it would be purely speculative to assume that any substantial number of inappropriate interventions would be caused by the statute. Regardless, we do not believe that anything in the rule requires or fosters such a result.

We cannot make a confident estimate as to just how many cases there may be in which either the statute or the rule would make a difference. No comments provided a sound basis for such estimates. However, only a very small fraction of births involve any serious question of survival. Of these, only a fraction would not be treated appropriately under current medical practice, and would involve even a potential allegation of medical neglect. These considerations suggest that the potential number of cases which the statute might impact is not large. The number differentially affected by any particular wording of the rule itself would be far smaller. Taking into account typical costs of treatment for infants requiring intensive neonatal care, we conclude that the total costs due to the rule would not reach the thresholds of the Executive Order.

Procedural, Legal, and Administrative Costs

Similar reasoning applies to procedural and administrative costs. Here, we agree that the statute may make a larger relative difference, since it newly involves most States' child abuse agency and procedures, and encourages hospitals to create new Infant Care Review Committees. And here the relevant universe includes not only the cases where decisions are different, but also the potentially far larger number of cases undergoing review as well as the need to train staff and develop procedures.

With respect to the State agencies, real or suspected cases of abuse are already handled routinely. Infant care cases, though involving complex medical issues which may require the use of medical consultants, are no different in principle than other cases. And, as pointed out above, medical neglect is already covered by State laws. Federal grants to State agencies have increased from $6.7 million in fiscal year 1984 to $9 million plus $3 million specifically for implementation of these new requirements in fiscal year 1985. While we do not have a quantitative estimate of incremental costs to State agencies at this time, we do not believe that a serious resource problem exists.

With the emphasis on the voluntary nature of the suggested guidelines for Infant Care Review Committees, most of the specific concerns as to disruption of or overlap with other hospital functions should be eliminated. Many hospitals already have some kind of review process, and the number of committees, though small, has increased in recent years. Others will elect to create a new process, similar if not identical to our guidelines. Because any such process is voluntary, costs are not caused by this rule. Regardless, in the light of extensive parental, medical, and other consultative involvement which almost invariably occurs already in extreme cases, net additional resources need not be large. This is particularly so because the clearinghouses which the Department is funding will make obtaining expert medical advice and information relatively easy. Relative to both overall hospital revenues and resources devoted to intensive care of infants, these costs should be exceedingly low.

Legal and enforcement costs for cases in controversy will depend largely on the number of violations and suspected violations of the law. Very few cases should require legal action to assure needed treatment, particularly if Infant Care Review Committees or alternative arrangements perform their duties conscientiously.

Conclusion

In the light of the factors discussed above, the Department has determined that this is not a major rule under E.O. 12291, and certifies that a regulatory flexibility analysis is not required.

Paperwork Reduction Act

Under the Paperwork Reduction Act of 1980 the Department is required to submit to the Office of Management and Budget (OMB) for review and approval any information collection requirements in a proposed or final rule. The Department did submit § 1340.15 of the NPRM to OMB for their review under section 3504(h) of the Paperwork Reduction Act of 1980, and OMB assigned a control number (0980-0165). However, since the requirements are being revised by adding a new § 1340.15(c)(3) and expanding § 1340.15(c)(4), we are required to resubmit the information collection requirements contained in § 1340.15 to OMB for their approval. A notice will be published in the Federal Register when approval is obtained.

List of Subjects in 45 CFR Part 1340

Child welfare, Disabled, Family violence, Grants programs-health, Grant programs-social programs.

(Catalog of Federal Domestic Assistance Program No. 13.628, Child Abuse and Neglect Prevention and Treatment)

For the reasons set forth in the preamble, 45 CFR Part 1340 is amended as follows:

1. The Table of Contents is amended by adding a new section, § 1340.15 "Services and treatment for disabled infants," and a new listing "Appendix—Interpretative Guidelines Regarding 45 CFR 1340.15—Services and Treatment for Disabled Infants." As revised, the table of contents reads as follows:

PART 1340—CHILD ABUSE AND NEGLECT PREVENTION AND TREATMENT

Subpart A—General Provisions

Sec.
1340.1 Purpose and scope.
1340.2 Definitions.
1340.3 Applicability of Department-wide regulations.
1340.4 Coordination requirements.

Subpart B—Grants to States

1340.10 Purpose of this subpart.
1340.11 Allocation of funds available.
1340.12 Application process.
1340.13 Approval of applications.
1340.14 Eligibility requirements.
1340.15 Services and treatment for disabled infants.

Subpart C—Discretionary Grants and Contracts

1340.20 Confidentiality.

Appendix—Interpretative Guidelines Regarding 45 CFR 1340.15—Services and Treatment for Disabled Infants.

2. The authority citation for Part 1340 is revised to read as follows:

Authority: Child Abuse Prevention and Treatment Act, Pub. L. 93-247, 88 Stat. 4; Pub. L. 95-266, 92 Stat. 205, Sections 600-610; Pub. L. 97-35, 95 Stat. 488; Pub. L. 98-457, 98 Stat. 1749 (42 U.S.C. 5101 et seq. and 42 U.S.C. 5101 note)

3. The introductory text of § 1340.14, Eligibility requirements is revised to read as follows:

§ 1340.14 Eligibility requirements.

In order for a State to qualify for an award under this subpart, the State must meet the requirements of § 1340.15 and satisfy each of the following requirements:

* * * * *

4. A new § 1340.15 is added to Subpart B—Grants to States, to read as follows:

§ 1340.15 Services and treatment for disabled infants.

(a) *Purpose.* The regulations in this section implement certain provisions of the Child Abuse Amendments of 1984 including section 4(b)(2)(K) of the Child Abuse Prevention and Treatment Act governing the protection and care of disabled infants with life-threatening conditions.

(b) *Definitions.* (1) The term "medical neglect" means the failure to provide adequate medical care in the context of the definitions of "child abuse and neglect" in section 3 of the Act and § 1340.2(d) of this part. The term "medical neglect" includes, but is not limited to, the withholding of medically indicated treatment from a disabled infant with a life-threatening condition.

(2) The term "withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's (or physicians') reasonable medical judgment any of the following circumstances apply:

(i) The infant is chronically and irreversibly comatose;

(ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or

(iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

(3) Following are definitions of terms used in paragraph (b)(2) of this section:

(i) The term "infant" means an infant less than one year of age. The reference to less than one year of age shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age. In addition to their applicability to infants less than one year of age, the standards set forth in paragraph (b)(2) of this section should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability.

(ii) The term "reasonable medical judgment" means a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.

(c) *Eligibility Requirements.* (1) In addition to the other eligibility requirements set forth in this Part, to qualify for a grant under this section, a State must have programs, procedures, or both, in place within the State's child protective service system for the purpose of responding to the reporting of medical neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions.

(2) These programs and/or procedures must provide for:

(i) Coordination and consultation with individuals designated by and within appropriate health care facilities;

(ii) Prompt notification by individuals designated by and within appropriate health care facilities of cases of suspected medical neglect (including instances of the withholding of medically indicated treatment from disabled infants with life-threatening conditions); and

(iii) The authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

(3) The programs and/or procedures must specify that the child protective services system will prompty contact each health care facility to obtain the name, title, and telephone number of the individual(s) designated by such facility for the purpose of the coordination, consultation, and notification activities identified in paragraph (c)(2) of this section, and will at least annually recontact each health care facility to obtain any changes in the designations.

(4) These programs and/or procedures must be in writing and must conform with the requirements of section 4(b)(2) of the Act and § 1340.14 of this part.

In connection with the requirement of conformity with the requirements of section 4(b)(2) of the Act and § 1340.14 of this part, the programs and/or procedures must specify the procedures the child protective services system will follow to obtain, in a manner consistent with State law:

(i) Access to medical records and/or other pertinent information when such access is necessary to assure an appropriate investigation of a report of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life threatening conditions); and

(ii) A court order for an independent medical examination of the infant, or otherwise effect such an examination in accordance with processes established under State law, when necessary to assure an appropriate resolution of a report of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life threatening conditions).

(5) The eligibility requirements contained in this section shall be effective October 9, 1985.

(d) *Documenting eligibility.* (1) In addition to the information and documentation required by and pursuant to § 1340.12(b) and (c), each State must submit with its application for a grant sufficient information and documentation to permit the Commissioner to find that the State is in compliance with the eligibility requirements set forth in paragraph (c) of this section.

(2) This information and documentation shall include:

(i) A copy of the written programs and/or procedures established by, and followed within, the State for the purpose of responding to the reporting of medical neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions;

(ii) Documentation that the State has authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to inititate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions. This documentation shall consist of:

(A) A copy of the applicable provisions of State statute(s); or

(B) A copy of the applicable provisions of State rules or regulations, along with a copy of the State statutory provisions that provide the authority for such rules or regulations; or

(C) A copy of an official, numbered opinion of the Attorney General of the State that so provides, along with a copy of the applicable provisions of the State statute that provides a basis for the opinion, and a certification that the official opinion has been distributed to interested parties within the State, at least including all hospitals; and

(iii) Such other information and documentation as the Commissioner may require.

(e) *Regulatory construction.* (1) No provision of this section or part shall be construed to affect any right, protection, procedures, or requirement under 45 CFR Part 84, Nondiscrimination in the Basis of Handicap in Programs and Activities Receiving or Benefiting from Federal Financial Assistance.

(2) No provision of this section or part may be so construed as to authorize the Secretary or any other governmental entity to establish standards prescribing specific medical treatments for specific conditions, except to the extent that

such standards are authorized by other laws or regulations.

5. 45 CFR Part 1340 is further amended by adding at the end thereof the following Appendix:

APPENDIX TO PART 1340—Interpretative Guidelines Regarding 45 CFR 1340.15—Services and Treatment for Disabled Infants

This appendix sets forth the Department's interpretative guidelines regarding several terms that appear in the definition of the term "withholding of medically indicated treatment" in section 3(3) of the Child Abuse Prevention and Treatment Act, as amended by section 121(3) of the Child Abuse Amendments of 1984. This statutory definition is repeated in § 1340.15(b)(2) of the final rule.

The Department's proposed rule to implement those provisions of the Child Abuse Amendments of 1984 relating to services and treatment for disabled infants included a number of proposed clarifying definitions of several terms used in the statutory definition. The preamble to the proposed rule explained these proposed clarifying definitions, and in some cases used examples of specific diagnoses to elaborate on meaning.

During the comment period on the proposed rule, many commenters urged deletion of these clarifying definitions and avoidance of examples of specific diagnoses. Many commenters also objected to the specific wording of some of the proposed clarifying definitions, particularly in connection with the proposed use of the word "imminent" to describe the proximity in time at which death is anticipated regardless of treatment in relation to circumstances under which treatment (other than appropriate nutrition, hydration and medication) need not be provided. A letter from the six principal sponsors of the "compromise amendment" which became the pertinent provisions of the Child Abuse Amendments of 1984 urged deletion of "imminent" and careful consideration of the other concerns expressed.

After consideration of these recommendations, the Department decided not to adopt these several proposed clarifying definitions as part of the final rule. It was also decided that effective implementation of the program established by the Child Abuse Amendments would be advanced by the Department stating its interpretations of several key terms in the statutory definition. This is the purpose of this appendix.

The interpretative guidelines that follow have carefully considered comments submitted during the comment period on the proposed rule. These guidelines are set forth and explained without the use of specific diagnostic exmples to elaborate on meaning.

Finally, by way of introduction, the Department does not seek to establish these interpretative guidelines as binding rules of law, nor to prejudge the exercise of reasonable medical judgment in responding to specific circumstances. Rather, this guidance is intended to assist in interpreting the statutory definition so that it may be rationally and thoughtfully applied in specific contexts in a manner fully consistent with the legislative intent.

1. *In general: the statutory definition of "withholding of medically indicated treatment."*

Section 1340.15(b)(2) of the final rule defines the term "withholding of medically indicated treatment" with a definition identical to that which appears in section 3(3) of the Act (as amended by section 121(3) of the Child Abuse Amendments of 1984).

This definition has several main features. First, it establishes the basic principle that all disabled infants with life-threatening conditions must be given medically indicated treatment, defined in terms of action to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration or medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions.

Second, the statutory definition spells out three circumstances under which treatment is not considered "medically indicated." These are when, in the treating physician's (or physicians') reasonable medical judgment:

—The infant is chronically and irreversibly comatose;

—The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of survival of the infant; or

—The provision of such treatment would be virtually futile in terms of survival of the infant and the treatment itself under such circumstances would be inhumane.

The third key feature of the statutory definition is that even when one of these three circumstances is present, and thus the failure to provide treatment is not a "withholding of medically indicated treatment," the infant must nonetheless be provided with appropriate nutrition, hydration, and medication.

Fourth, the definition's focus on the potential effectiveness of treatment in ameliorating or correcting life-threatening conditions makes clear that it does not sanction decisions based on subjective opinions about the future "quality of life" of a retarded or disabled person.

The fifth main feature of the statutory definition is that its operation turns substantially on the "reasonable medical judgment" of the treating physician or physicians. The term "reasonable medical judgment" is defined in § 1340.15(b)(3)(ii) of the final rule, as it was in the Conference Committee Report on the Act, as a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.

The Department's interpretations of key terms in the statutory definition are fully consistent with these basic principles reflected in the definition. The discussion that follows is organized under headings that generally correspond to the proposed clarifying definitions that appeared in the proposed rule but were not adopted in the final rule. The discussion also attempts to analyze and respond to significant comments received by the Department.

2. *The term "life-threatening condition".*

Clause (b)(3)(ii) of the proposed rule proposed a definition of the term "life-threatening condition." This term is used in the statutory definition in the following context:

> [T]he term "withholding of medically indicated treatment" means the failure to respond to the infant's *life-threatening conditions* by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions [, except that] * * *. [Emphasis supplied].

It appears to the Department that the applicability of the statutory definition might be uncertain to some people in cases where a condition may not, strictly speaking, by itself be life-threatening, but where the condition significantly increases the risk of the onset of complications that may threaten the life of the infant. If medically indicated treatment is available for such a condition, the failure to provide it may result in the onset of complications that, by the time the condition becomes life-threatening in the strictest sense, will eliminate or reduce the potential effectiveness of any treatment. Such a result cannot, in the Department's view, be squared with the Congressional intent.

Thus, the Department interprets the term "life-threatening condition" to include a condition that, in the treating physician's or physicians' reasonable medical judgment, significantly increases the risk of the onset of complications that may threaten the life of the infant.

In response to comments that the proposed rule's definition was potentially overinclusive by covering any condition that one could argue "may" become life-threatening, the Department notes that the statutory standard of "the treating physician's or physicians' reasonable medical judgment" is incorporated in the Department's interpretation, and is fully applicable.

Other commenters suggested that this interpretation would bring under the scope of the definition many irreversible conditions for which no corrective treatment is available. This is certainly not the intent. The Department's interpretation implies nothing about whether, or what, treatment should be provided. It simply makes clear that the criteria set forth in the statutory definition for evaluating whether, or what, treatment should be provided are applicable. That is just the start, not the end, of the analysis. The analysis then takes fully into account the reasonable medical judgment regarding potential effectiveness of possible treatments and the like.

Other comments were that it is unnecessary to state any interpretation because reasonable medical judgment commonly deems the conditions described as life-threatening and responds accordingly. HHS agrees that this is common practice followed under reasonable medical judgment just as all the standards incorporated in the statutory definition reflect common practice followed under reasonable medical judgment. For the reasons stated above, however, the Department believes it is useful to say so in these interpretative guidelines.

3. *The term "treatment" in the context of adequate evaluation.*

Clause (b)(3)(ii) of the proposed rule proposed a definition of the term "treatment." Two separate concepts were dealt with in clause (A) and (B), respectively, of the proposed rule. Both of these clauses were designed to ensure that the Congressional intent regarding the issues to be considered under the analysis set forth in the statutory definition is fully effectuated. Like the guidance regarding "life-threatening condition," discussed above, the Department's interpretations go to the applicability of the statutory analysis, not its result.

The Department believes that Congress intended that the standard of following reasonable medical judgment regarding the potential effectiveness of possible courses of action should apply to issues regarding adequate medical evaluation, just as it does to issues regarding adequate medical intervention. This is apparent Congressional intent because Congress adopted, in the Conference Report's definition of "reasonable medical judgment," the standard of adequate knowledge about the case and the treatment possibilities with respect to the medical condition involved.

Having adequate knowledge about the case and the treatment possibilities involved is, in effect, step one of the process, because that is the basis on which "reasonable medical judgment" will operate to make recommendations regarding medical intervention. Thus, part of the process to determine what treatment, if any, "will be most likely to be effective in ameliorating or correcting" all life-threatening conditions is for the treating physician or physicians to make sure they have adequate information about the condition and adequate knowledge about treatment possibilities with respect to the condition involved. The standard for determining the adequacy of the information and knowledge is the same as the basic standard of the statutory definition: reasonable medical judgment. A reasonably prudent physician faced with a particular condition about which he or she needs additional information and knowledge of treatment possibilities would take steps to gain more information and knowledge by, quite simply, seeking further evaluation by, or consultation with, a physician or physicians whose expertise is appropriate to the condition(s) involved or further evaluation at a facility with specialized capabilities regarding the conditions(s) involved.

Thus, the Department interprets the term "treatment" to include (but not be limited to) any further evaluation by, or consultation with, a physician or physicians whose expertise is appropriate to the condition(s) involved or further evaluation at a facility with specialized capabilities regarding the condition(s) involved that, in the treating physician's or physicians' reasonable medical judgment, is needed to assure that decisions regarding medical intervention are based on adequate knowledge about the case and the treatment possibilities with respect to the medical conditions involved.

This reflects the Department's interpretation that failure to respond to an infant's life-threatening conditions by obtaining any further evaluations or consultations that, in the treating physician's reasonable medical judgment, are necessary to assure that decisions regarding medical intervention are based on adequate knowledge about the case and the treatment possibilities involved constitutes a "withholding of medically indicated treatment." Thus, if parents refuse to consent to such a recommendation that is based on the treating physician's reasonable medical judgment that, for example, further evaluation by a specialist is necessary to permit reasonable medical judgments to be made regarding medical intervention, this would be a matter for appropriate action by the child protective services system.

In response to comments regarding the related provision in the proposed rule, this interpretative guideline makes quite clear that this interpretation does not deviate from the basic principle of reliance on reasonable medical judgment to determine the extent of the evaluations necessary in the particular case. Commenters expressed concerns that the provision in the proposed rule would intimidate physicians to seek transfer of seriously ill infants to tertiary level facilities much more often than necessary, potentially resulting in diversion of the limited capacities of these facilities away from those with real needs for the specialized care, unnecessary separation of infants from their parents when equally beneficial treatment could have been provided at the community or regional hospital, inappropriate deferral of therapy while time-consuming arrangements can be affected, and other counterproductive ramifications. The Department intended no intimidation, prescription or similar influence on reasonable medical judgment, but rather, intended only to affirm that it is the Department's interpretation that the reasonable medical judgment standard applies to issues of medical evaluation, as well as issues of medical intervention.

4. *The term "treatment" in the context of multiple treatments.*

Clause (b)(3)(iii)(B) of the proposed rule was designed to clarify that, in evaluating the potential effectiveness of a particular medical treatment or surgical procedure that can only be reasonably evaluated in the context of a complete potential treatment plan, the "treatment" to be evaluated under the standards of the statutory definition includes the multiple medical treatments and/or surgical procedures over a period of time that are designed to ameliorate or correct a life-threatening condition or conditions. Some commenters stated that it could be construed to require the carrying out of a long process of medical treatments or surgical procedures regardless of the lack of success of those done first. No such meaning is intended.

The intent is simply to characterize that which must be evaluated under the standards of the statutory definition, not to imply anything about the results of the evaluation. If parents refuse consent for a particular medical treatment or surgical procedure that by itself may not correct or ameliorate all life-threatening conditions, but is recommended as part of a total plan that involves multiple medical treatments and/or surgical procedures over a period of time that, in the treating physician's reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, that would be a matter for appropriate action by the child protective services system.

On the other hand, if, in the treating physician's reasonable medical judgment, the total plan will, for example, be virtually futile and inhumane, within the meaning of the statutory term, then there is no "withholding of medically indicated treatment." Similarly, if a treatment plan is commenced on the basis of a reasonable medical judgment that there is a good chance that it will be effective, but due to a lack of success, unfavorable complications, or other factors, it becomes the treating physician's reasonable medical judgment that further treatment in accord with the prospective treatment plan, or alternative treatment, would be futile, then the failure to provide that treatment would not constitute a "withholding of medically indicated treatment." This analysis does not divert from the reasonable medical judgment standard of the statutory definition; it simply makes clear the Department's interpretation that the failure to evaluate the potential effectiveness of a treatment plan as a whole would be inconsistent with the legislative intent.

Thus, the Department interprets the term "treatment" to include (but not be limited to) multiple medical treatments and/or surgical procedures over a period of time that are designed to ameliorate or correct a life-threatening condition or conditions.

5. *The term "merely prolong dying."*

Clause (b)(3)(v) of the proposed rule proposed a definition of the term "merely prolong dying," which appears in the statutory definition. The proposed rule's provision stated that this term "refers to situations where death is imminent and treatment will do no more than postpone the act of dying."

Many commenters argued that the incorporation of the word "imminent," and its connotation of immediacy, appeared to deviate from the Congressional intent, as developed in the course of the lengthy legislative negotiations, that reasonable medical judgments can and do result in nontreatment decisions regarding some conditions for which treatment will do no more than temporarily postpone a death that will occur in the near future, but not necessarily within days. The six principal sponsors of the compromise amendment also strongly urged deletion of the word "imminent."

The Department's use of the term "imminent" in the proposed rule was not intended to convey a meaning not fully consonant with the statute. Rather, the Department intended that the word "imminent" would be applied in the context of the condition involved, and in such a context, it would not be understood to specify a particular number of days. As noted in the preamble to the proposed rule, this clarification was proposed to make clear that the "merely prolong dying" clause of the statutory definition would not be applicable to situations where treatment will not totally correct a medical condition but will give a patient many years of life. The Department continues to hold to this view.

To eliminate the type of misunderstanding evidenced in the comments, and to assure consistency with the statutory definition, the word "imminent" is not being adopted for purposes of these interpretative guidelines.

The Department interprets the term "merely prolong dying" as referring to situations where the prognosis is for death and, in the treating physician's (or physicians') reasonable medical judgment, further or alternative treatment would not alter the prognosis in an extension of time that would not render the treatment futile.

Thus, the Department continues to interpret Congressional intent as not permitting the "merely prolong dying" provision to apply where many years of life will result from the provision of treatment, or where the prognosis is not for death in the near future, but rather the more distant future. The Department also wants to make clear it does not intend the connotations many commenters associated with the word "imminent." In addition, contrary to the impression some commenters appeared to have regarding the proposed rule, the Department's interpretation is that reasonable medical judgments will be formed on the basis of knowledge about the condition(s) involved, the degree of inevitability of death, the probable effect of any potential treatments, the projected time period within which death will probably occur, and other pertinent factors.

6. *The term "not be effective in ameliorating or correcting all of the infant's life threatening conditions" in the context of a future life-threatening condition.*

Clause (b)(3)(vi) of the proposed rule proposed a definition of the term "not be effective in ameliorating or correcting all the infant's life-threatening conditions" used in the statutory definition of "withholding of medically indicated treatment."

The basic point made by the use of this term in the statutory definition was explained in the Conference Committee Report:

> Under the definition, if a disabled infant suffers from more than one life-threatening condition and, in the treating physician's or physicians' reasonable medical judgment, there is no effective treatment for one of those conditions, then the infant is not covered by the terms of the amendment (except with respect to appropriate nutrition, hydration, and medication) concerning the withholding of medically indicated treatment.

H. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 41 (1980).

This clause of the proposed rule dealt with the application of this concept in two contexts: first, when the nontreatable condition will not become life-threatening in the near future, and second, when humaneness makes palliative treatment medically indicated.

With respect to the context of a future life-threatening condition, it is the Department's interpretation that the term "not be effective in ameliorating or correcting all of the infant's life-threatening conditions" does not permit the withholding of treatment on the grounds that one or more of the infant's life-threatening conditions, although not life-threatening in the near future, will become life-threatening in the more distant future.

This clarification can be restated in the terms of the Conference Committee Report excerpt, quoted just above, with the italicized words indicating the clarification, as follows:

> Under the definition, if a disabled infant suffers from more than one life-threatening condition and, in the treating physician's or physicians' reasonable medical judgment, there is no effective treatment for one of these conditions *that threatens the life of the infant in the near future*, then the infant is not covered by the terms of the amendment (except with respect to appropriate nutrition, hyrdation, and medication) concerning the withholding of medically indicated treatment; *but if the nontreatable condition will not become life-threatening until the more distant future, the infant is covered by the terms of the amendment.*

Thus, this interpretative guideline is simply a corollary to the Department's interpretation of "merely prolong dying," stated above, and is based on the same understanding of Congressional intent, indicated above, that if a condition will not become life-threatening until the more distant future, it should not be the basis for withholding treatment.

Also for the same reasons explained above, the word "imminent" that appeared in the proposed definition is not adopted for purposes of this interpretative guideline. The Department makes no effort to draw an exact line to separate "near future" from "more distant future." As noted above in connection with the term "merely prolong dying," the statutory definition provides that it is for reasonable medical judgment, applied to the specific condition and circumstances involved, to determine whether the prognosis of death, because of its nearness in time, is such that treatment would not be medically indicated.

7. *The term "not be effective in ameliorating or correcting all life-threatening conditions" in the context of palliative treatment.*

Clause (b)(3)(iv)(B) of the proposed rule proposed to define the term "not be effective in ameliorating or correcting all life-threatening conditions" in the context where the issue is not life-saving treatment, but rather palliative treatment to make a condition more tolerable. An example of this situation is where an infant has more than one life-threatening condition, at least one of which is not treatable and will cause death in the near future. Palliative treatment is available, however, that will, in the treating physician's reasonable medical judgment, relieve severe pain associated with one of the conditions. If it is the treating physician's reasonable medical judgment that this palliative treatment will ameliorate the infant's *overall* condition, taking all individual conditions into account, even though it would not ameliorate or correct *each* condition, then this palliative treatment is medically indicated. Simply put, in the context of ameliorative treatment that will make a condition more tolerable, the term "not be effective in ameliorating or correcting *all* life-threatening conditions" should not be construed as meaning *each and every* condition, but rather as referring to the infant's *overall* condition.

HHS believes Congress did not intend to exclude humane treatment of this kind from the scope of "medically indicated treatment." The Conference Committee Report specifically recognized that "it is appropriate for a physician, in the exercise of reasonable medical judgment, to consider that factor [humaneness] in selecting among effective treatments." H. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 41 (1984). In addition, the articulation in the statutory definition of circumstances in which treatment need not be provided specifically states that "appropriate nutrition, hydration, and medication" must nonetheless be provided. The inclusion in this proviso of medication, one (but not the only) potential palliative treatment to relieve severe pain, corroborates the Department's interpretation that such palliative treatment that will ameliorate the infant's overall condition, and that in the exercise of reasonable medical judgment is humane and medically indicated, was not intended by Congress to be outside the scope of the statutory definition.

Thus, it is the Department's interpretation that the term "not be effective in ameliorating or correcting all of the infant's life-threatening conditions" does not permit the withholding of ameliorative treatment that, in the treating physician's or physicians' reasonable medical judgment, will make a condition more tolerable, such as providing palliative treatment to relieve severe pain, even if the overall prognosis, taking all conditions into account, is that the infant will not survive.

A number of commenters expressed concerns about some of the examples contained in the preamble of the proposed rule that discussed the proposed definition relating to this point, and stated that, depending on medical complications, exact prognosis, relationships to other conditions, and other factors, the treatment suggested in the examples might not necessarily be the treatment that reasonable medical judgment would decide would be most likely to be effective. In response to these comments, specific diagnostic examples have not been included in this discussion, and this interpretative guideline makes clear that the "reasonable medical judgment" standard applies on this point as well.

Other commenters argued that an interpretative guideline on this point is unnecessary because reasonable medical judgment would commonly provide ameliorative or palliative treatment in the circumstances described. The Department agrees that such treatment is common in the exercise of reasonable medical judgment, but believes it useful, for the reasons stated, to provide this interpretative guidance.

8. *The term "virtually futile".*

Clause (b)(3)(vii) of the proposed rule proposed a definition of the term "virtually futile" contained in the statutory definition

The context of this term in the statutory definition is:

> [T]he term "withholding of medically indicated treatment" * * * does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, * * * the provision of such treatment would be *virtually futile* in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. Section 3(3)(C) of the Act [emphasis supplied].

The Department interprets the term "virtually futile" to mean that the treatment is highly unlikely to prevent death in the near future.

This interpretation is similar to those offered in connection with "merely prolong dying" and "not be effective in ameliorating or correcting all life-threatening conditions" in the context of a future life-threatening condition, with the addition of a characterization of likelihood that corresponds to the statutory word "virtually." For the reasons explained in the discussion of "merely prolong dying," the word "imminent" that was used in the proposed rule has not been adopted for purposes of this interpretative guideline.

Some commenters expressed concern regarding the words "highly unlikely," on the grounds that such certitude is often medically impossible. Other commenters urged that a distinction should be made between generally utilized treatments and experimental treatments. The Department does not believe any special clarifications are needed to respond to these comments. The basic standard of reasonable medical judgment applies to the term "virtually futile." The Department's interpretation does not suggest an impossible or unrealistic standard of certitude for any medical judgment. Rather, the standard adopted in the law is that there be a "reasonable medical judgment." Similarly, reasonable medical judgment is the standard for evaluating potential treatment possibilities on the basis of the actual circumstances of the case. HHS does not believe it would be helpful to try to establish distinctions based on characterizations of the degree of general usage, extent of validated efficacy data, or other similar factors. The factors considered in the exercise of reasonable medical judgment, including any factors relating to human subjects experimentation standards, are not disturbed.

9. *The term "the treatment itself under such circumstances would be inhumane."*

Clause (b)(3)(viii) of the proposed rule proposed a definition of the term "the treatment itself under such circumstances would be inhumane," that appears in the statutory definition. The context of this term in the statutory definition is that it is not a "withholding of medically indicated treatment" to withhold treatment (other than appropriate nutrition, hydration, or medication) when, in the treating physician's reasonable medical judgment, "the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane." § 3(3)(C) of the Act.

The Department interprets the term "the treatment itself under such circumstances would be inhumane" to mean the treatment itself involves significant medical contraindications and/or significant pain and suffering for the infant that clearly outweigh the very slight potential benefit of the treatment for an infant highly unlikely to survive. (The Department further notes that the use of the term "inhumane" in this context is not intended to suggest that consideration of the humaneness of a particular treatment is not legitimate in any other context; rather, it is recognized that it is appropriate for a physician, in the exercise of reasonable medical judgment, to consider that factor in selecting among effective treatments.)

Other clauses of the statutory definition focus on the expected *result* of the possible treatment. This provision of the statutory definition adds a consideration relating to the *process* of possible treatment. It recognizes that in the exercise of reasonable medical judgment, there are situations where, although there is some slight chance that the treatment will be beneficial to the patient (the potential treatment is considered *virtually* futile, rather than futile), the potential benefit is so outweighed by negative factors relating to the process of the treatment itself that, under the circumstances, it would be inhumane to subject the patient to the treatment.

The Department's interpretation is designed to suggest the factors that should be taken into account in this difficult balance. A number of commenters argued that the interpretation should permit, as part of the evaluation of whether treatment would be inhumane, consideration of the infant's future "quality of life."

The Department strongly believes such an interpretation would be inconsistent with the statute. The statute specifies that the provision applies only where the treatment would be "virtually futile in terms of the survival of the infant," and the "treatment *itself* under such circumstances would be inhumane." (Emphasis supplied.) The balance is clearly to be between the very slight chance that treatment will allow the infant to survive and the negative factors relating to the process of the treatment. These are the circumstances under which reasonable medical judgment could decide that the treatment itself would be inhumane.

Some commenters expressed concern about the use of terms such as "clearly outweight" in the description of this balance on the grounds that such precision is impractical. Other commenters argued that this interpretation could be construed to mandate useless and painful treatment. The Department believes there is no basis for these worries because "reasonable medical judgment" is the governing standard. The interpretative guideline suggests nothing other than application of this standard. What the guideline does is set forth the Department's interpretation that the statute directs the reasonable medical judgment to considerations relating to the slight chance of survival and the negative factors regarding the process of treatment and to the balance between them that would support a conclusion that the treatment itself would be inhumane.

Other commenters suggested adoption of a statement contained in the Conference Committee Report that makes clear that the use of the term "inhumane" in the statute was not intended to suggest that consideration of the humaneness of a particular treatment is not legitimate in any other context. The Department has adopted this statement as part of its interpretative guideline.

10. *Other terms.*

Some comments suggested that the Department clarify other terms used in the statutory definition of "withholding of medically indicated treatment," such as the term "appropriate nutrition, hydration or medication" in the context of treatment that may not be withheld, notwithstanding the existence of one of the circumstances under which the failure to provide treatment is not a "withholding of medically indicated treatment." Some commenters stated, for example, that very potent pharmacologic agents, like other methods of medical intervention, can produce results accurately described as accomplishing no more than to merely prolong dying, or be futile in terms of the survival of the infant, or the like, and that, therefore, the Department should clarify that the proviso regarding "appropriate nutrition, hydration or medication" should not be construed entirely independently of the circumstances under which other treatment need not be provided.

The Department has not adopted an interpretative guideline on this point because it appears none is necessary. As noted above in the discussion of palliative treatment, the Department recognizes that there is no absolutely clear line between medication and treatment other than medication that would justify excluding the latter from the scope of palliative treatment that reasonable medical judgment would find medically indicated, notwithstanding a very poor prognosis.

Similarly, the Department recognizes that in some circumstances, certain pharmacologic agents, not medically indicated for palliative purposes, might, in the exercise of reasonable medical judgment, also not be indicated for the purpose of correcting or ameliorating any particular condition because they will, for example, merely prolong dying. However, the Department believes the word "appropriate" in this proviso of the statutory definition is adequate to permit the exercise of reasonable medical judgment in the scenario referred to by these commenters.

At the same time, it should be clearly recognized that the statute is completely unequivocal in requiring that all infants receive "appropriate nutrition, hydration, and medication," regardless of their condition or prognosis.

Dated: March 29, 1985.

Dorcas R. Hardy,

Assistant Secretary for Human Development Services.

Approved: April 5, 1985.

Margaret M. Heckler,

Secretary.

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Human Development Services

Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers To Establish Infant Care Review Committees

AGENCY: Office of Human Development Services, HHS.

ACTION: Model Guidelines for Health Care Providers to Establish Infant Care Review Committees.

SUMMARY: These are model guidelines to encourage the establishment within health care facilities, especially facilities with tertiary level neonatal care units, of committees for the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment (including appropriate nutrition, hydration, and medication) from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions. The publication of these model guidelines is required by section 124(b) of the Child Abuse Amendments of 1984, Pub. L. 98-457.

FOR FURTHER INFORMATION CONTACT: Jay Olson at (202) 245-2859.

SUPPLEMENTARY INFORMATION: These model guidelines are being issued in accordance with section 124(b) of the Child Abuse Amendments of 1984, Pub. L. 98-457. Pursuant to this section, these guidelines encourage hospitals that provide health care to infants to establish Infant Care Review Committees (ICRCs).

As required by the Act, interim model guidelines were published for public comment December 10, 1984, 45 FR 48170, and a 60-day comment period was provided. The Department received many comments regarding the interim model guidelines. These comments have been carefully considered. The appendix to the model guidelines is an analysis of significant comments received during the comment period.

The principles, policies and procedures set forth in this model represent the Department's best judgments, informed by a careful review of the comments submitted, regarding the most effective formulation for review committees. The Department encourages hospitals that provide care to infants, especially facilities with tertiary level neonatal care units, to establish ICRC's, and to consider fully the provisions set forth in the Department's suggested model.

Infant Care Review Committees—Model Guidelines

I. Introduction

In the past several years there has been substantially heightened public attention to issues relating to treatment and services for disabled infants. This increased attention has fueled, and has been fueled by, controversy regarding existing patterns of medical care decision-making and various proposals and initiatives to affect those patterns.

Amidst this controversy, one proposal that has gained widespread support is the establishment of hospital-based committees as the forum and focal point for efforts to assure that medical treatment decisions are informed, thoughtful and consistent with proper medical standards. The thrust of this proposal was well articulated in the March 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

> The Commission concludes that hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants. . . . Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone. . . .
>
> Such a review could serve several functions and the review mechanism may vary accordingly. First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate.

Subsequent to this report, a broad range of medical and health associations endorsed the concept of hospital review committees to deal with issues relating to medical care for disabled infants. These associations include the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, the American Hospital Association, the American Medical Association, the Catholic Health Association, the Federation of American Hospitals, the American College of Hospital Administrators, the American College of Physicians, the American Nurses Association, and others. Some of these associations, as well as other organizations, have developed model guidelines for committees.

Most recently, this proposal was strongly endorsed by the United States Congress in Pub. L. 98-457, the "Child Abuse Amendments of 1984." In addition to provisions in that legislation requiring State child protective services agencies to establish procedures to prevent the "withholding of medically indicated treatment from disabled infants with life-threatening conditions," the law made it a matter of national policy to encourage the establishment of hospital committees. More specifically, this law, which was supported by an extraordinary coalition of medical associations and disability and other advocacy organizations, requires that:

> [T]he Secretary [of Health and Human Services] shall publish . . . model guidelines to encourage the establishment within health care facilities of committees which would serve the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment . . . from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions.
>
> Pub. L. No. 98-457, section 124.

The Department of Health and Human Services fully endorses the recommendation of the President's Commission and the adoption by Congress of the policy of encouraging the formation of these committees. What follows are the HHS model guidelines for the establishment and operation of Infant Care Review Committees.

The guidelines are purely advisory. They are not mandatory in any way. The establishment of an ICRC is not required by any Federal law, regulation, administrative policy, or condition of participation in any Federal program. Similarly, if a hospital chooses to establish an Infant Care Review Committee, there is no requirement of any kind that follows this model. In addition, the Department offers no legal, regulatory or administrative inducements or rewards for establishing an ICRC and/or following this model. Moreover, no legal responsibilities of the hospital, including those related to child protective services activities of the State, are removed or reduced by the estalishment of an ICRC and/or adoption of this model.

Rather, the Department's recommendation that hospitals establish Infant Care Review Committees and consider the elements of this model is based solely on the Department's firm agreement with the various endorsements, listed above, of the hospital review committee concept and the Department's judgment that the elements of this model are important to make the committee effective. The Department thus strongly encourages hospitals that provide care to infants, especially those with tertiary level neonatal care units, to establish Infant Care Review Committees, and to consider the provisions of these model guidelines.

II. Establishment and Purpose

HHS recommends that the hospital establish an Infant Care Review Committee (ICRC) or join with one or more other hospitals to create a joint ICRC. The purposes and functions of the Infant Care Review Committee are:

1. To educate hospital personnel and families of disabled infants with life-threatening conditions;
2. To recommend institutional policies and guidelines concerning the withholding of medically indicated treatment from disabled infants with life-threatening conditions; and
3. To offer counsel and review in cases involving disabled infants with life-threatening conditions.

III. Membership and Administration

A. *Membership of ICRC.*—The Department strongly recommends that the ICRC membership consist of individuals from varied disciplines and perspectives. A multi-disciplinary approach is important for the ICRC to have sufficient expertise to supply and evaluate all pertinent information to assist the committee in effectively carrying out its functions. The committee size should be large enough to represent diverse perspectives, but not so large as to hinder effectiveness. The Department recommends that the ICRC consists of at least the following core members:

1. A practicing physician (e.g., a pediatrician, a neonatologist, or a pediatric surgeon),
2. A practicing nurse,
3. A hospital administrator,
4. A social worker,
5. A representative of a disability group,
6. A lay community member, and
7. A member of the facility's organized medical staff, who shall serve as chairperson.

Consistent with the multi-disciplinary approach, the ICRC should consider supplementing the core membership with other permanent members, or through other formal methods, such as designating certain individuals as "advisors" to the ICRC, or through informal or ad hoc involvement. Among those that could be considered for such supplementation are: a representative of the clergy, a representative of the legal community (i.e., an attorney or judge), physicians with particular specialities pertinent to a policy or particular case under consideration, individuals with knowledge of issues affecting children and the families of children with certain disabilities, and other individuals with knowledge and perspectives valuable to effective action on particular functions and activities of the ICRC.

B. *Administration of the ICRC.*—The Department makes the following recommendations regarding administration of the ICRC:

1. The hospital should provide staff support for the ICRC, including legal counsel. The ICRC should meet on a regular basis or as recomended below in connection with review of specific cases. It should adopt or recommend to the appropriate hospital official or body such administrative policies as terms of office and quorum requirements.
2. The ICRC should recommend procedures to ensure that both hospital personnel and patient families are fully informed of the existence and functions of the ICRC and its availability to meet on a 24-hour basis.
3. The ICRC should carefully inform itself of all pertinent legal requirements and procedures, including pertinent provisions of State law requiring a report or notification to the appropriate State child protective services agency of known or suspected instances of medical neglect, including the withholding of medically indicated treatment (including appropriate nutrition, hydration, and medication) from disabled infants with life-threatening conditions and related procedures of the State agency.
4. The ICRC should maintain records of all of its deliberations and summary descriptions of specific cases considered and the disposition of those cases. Such records should be kept in accordance with institutional policies on confidentiality of medical information. They should be made available to appropriate government agencies, or upon court order, or as otherwise required by law.

IV. Educational Activities

A. *Basic Functions.*—The ICRC should act as a resource to hospital personnel and families of disabled infants with life-threatening conditions to provide current and complete information concerning medical treatment procedures and resources in the hospital and in other hospitals with which the hospital has referral agreements or to which patients may otherwise be referred. The ICRC should also act as a resource concerning available community services which may be needed for the provision of services and treatment for disabled infants with life-threatening conditions.

B. *Specific Activities.*—In order to carry out these functions, the ICRC should determine and make available to hospital personnel and families of disabled infants information regarding:

1. Available national and regional information and resource clearinghouses that provide pertinent information, such as the Computerized Handicapped Assistance Information Network ("CHAIN");
2. Facilities and agencies in the community and area that provide treatment and services, such as rehabilitative services and ongoing support, to disabled infants and children and their families;
3. Public and private programs and activities in the community and area, including organizations and associations that provide counselling and support for disabled children and their families and, when appropriate, adoption placement counselling and services; and
4. Other informational materials regarding medical treatment and rehabilitation procedures and resources and support activities.

V. Policy Development

A. *Basic Policy.* In recommending institutional policies and guidelines, the basic policy should be to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions. The definitions set forth below offer guidance regarding the substance of this basic policy. The definition of the term "withholding of medically indicated treatment" is that set forth in the Child Abuse Amendments of 1984 and specifically referenced by Congress in the provision of that law that encourages establishment of hospital committees.

1. The term "withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating

physician's or physicians' reasonable medical judgment—

(a) The infant is chronically and irreversibly comatose;

(b) The provision of such treatment would—

(1) Merely prolong dying,

(2) Not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or

(3) Otherwise be futile in terms of the survival of the infant; or

(c) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

2. The following are definitions of terms used in the definition of "medically indicated treatment."

(a) The term "infant" means an infant less than one year of age. The reference to one year of age does not imply that treatment should be changed or discontinued when an infant reaches one year of age or to affect or limit proper standards of medical care for children over one year of age. In addition to their applicability to infants less than one year of age, the standards set forth in the definition of "withholding of medically indicated treatment" in paragraph (1) should be consulted thoroughly in the evaluation of any issue of medical treatment involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability.

(b) The term "reasonable medical judgment" means medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.

3. HHS recommends that ICRC's also carefully review the Department's interpretative guidelines regarding terms used in the definition of "withholding of medically indicated treatment" (set forth in paragraph (1)) that appear in the appendix to the final rule implementing the provisions of the Child Abuse Amendments of 1984. The final rule will be codified at 45 CFR 1340.15, and the appendix will appear as an appendix to 45 CFR Part 1340.

B. *Development of Specific Policies and Guidelines*. 1. The Department recommends that the ICRC develop prospectively and recommend for adoption by the hospital institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions. These could include guidelines for management of specific types of cases or diagnoses that are likely to be seen in that facility and might present dilemmas in medical management, and procedures to be followed in such recurring circumstances. The hospital, upon recommendation of the ICRC, may wish to require attending physicians to notify the ICRC of the presence of the facility of an infant with a diagnosis specified by the ICRC.

2. In recommending these policies and guidelines, the ICRC should consult with medical and other authorities on issues involving treatment and services for disabled individuals, e.g., neonatologists, pediatric surgeons, and county and city agencies and disability advocacy organizations which provide services for the disabled. It should also consult with appropriate committees of the medical staff, to ensure that the ICRC policies and guidelines build on existing staff by-laws, rules and regulations concerning consultations and staff membership requirements. The ICRC should also make itself available to assist the hospital in its activities to inform and educate hospital staff on the policies and guidelines adopted by the hospital.

3. The Department recommends that the ICRC review existing procedures used by the hospital and/or recommend the adoption of new procedures to facilitate effective coordination and cooperation between the hospital and the State child protective services system with respect to that system's activities relating to preventing the withholding of medically indicated treatment from disabled infants with life-threatening conditions. These procedures should include: (a) Provisions regarding the responsibilities under State law for the hospital, physicians and other medical professionals to report to the child protective services agency suspected instances of medical neglect (including the withholding of medically indicated treatment from disabled infants with life-threatening conditions); (b) provisions regarding the designation of individuals (hereafter referred to as "designated individuals") within the hospital (who may, but need not be, members of the ICRC) to serve the liaison function with the child protective services agency in connection with the agency's programs and procedures for responding to the reporting of medical neglect (including the withholding of medically indicated treatment from disabled infants with life-threatening conditions); (c) procedures for coordination between the designated individuals and the ICRC in response to consultations initiated by the agency; (d) procedures for prompt notification by the designated individuals to the agency of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions); (e) procedures to facilitate compliance by the hospital and medical personnel of any and all other requirements of State law relating to activities of the child protective services system in connection with the system's programs and/or procedures concerning the withholding of medically indicated treatment from disabled infants with life-threatening conditions; and (f) such other procedures as may be appropriate to facilitate effective coordination and consultation between the hospital and medical personnel and the child protective services agency.

VI. Council and Review in Specific Cases

A major function of the Infant Care Review Committee is to review and offer counsel in specific cases involving disabled infants with life-threatening conditions. Set forth below are the procedures HHS recommends for carrying out this function in two contexts. The first context is prospective review of cases regarding infant patients concerning whom treatment decisions are being made or about whom there are otherwise issues of present or future treatment. The second context is retrospective review of cases concerning which there is then no issue of present or future treatment.

A. *Prospective Review and Counsel*. In addition to regularly scheduled meetings, emergency ICRC meetings should take place under specified circumstances to permit review of individual cases. The hospital should, to the extent possible, require in each case that life-sustaining treatment be continued, until the ICRC can review the case and provide advice.

1. Because of the need for prompt review and counsel, emergency ICRC meetings may have to be convened within 24 hours (or less if indicated). Such meetings should be convened when there is disagreement between the family of an infant and the infant's physician as to the withholding or withdrawal of treatment, when a preliminary decision to withhold or withdraw life-sustaining treatment has been made in certain categories of cases identified by the ICRC in its specific policies, when there is disagreement between members of the hospital's medical and/or nursing staffs, or when otherwise appropriate.

2. Such emergency ICRC meetings should take place upon the request of

any member of the ICRC or hospital staff or parent or guardian of the infant. The ICRC should have procedures to preserve the confidentiality of the identity of persons making such requests, and such persons should be protected from reprisal. When appropriate, the ICRC or a designated member should inform the requesting individual of the ICRC's recommendation.

3. The ICRC may provide for telephone and other forms of review when the timing and nature of the case, as identified in policies developed by the ICRC, make the convening of an emergency meeting impracticable.

4. Emergency meetings should be open to the affected parties. When appropriate to ensure informed discussion, a physician(s) experienced in the evaluation and treatment of the relevant disability(ies) or life-threatening condition(s) should be invited to attend. The ICRC should ensure that the interests of the parents, the physician, and the child are fully considered; that family members have been fully informed of the patient's condition and prognosis and that appropriate counselling services have been made available to them; and that they have been provided with a listing which describes, and any further information they need to facilitate their access to, the services furnished by parent support groups and public and private agencies in the geographic vicinity to infants with conditions such as that before the ICRC.

5. HHS recommends that to ensure a comprehensive evaluation of all options and factors pertinent to the committee's deliberations, the chairperson designate one member of the ICRC to act, in connection with that specific case, as "special advocate" for the infant. The special advocate should seek to ensure that all considerations in favor of the provision of additional treatment are fully evaluated and considered by the ICRC. The chairperson should make clear to all participants and observers that the designation of a "special advocate" is a standard procedural practice to ensure thorough deliberation, and that it does not imply that any other participant is less concerned about the welfare of the infant.

6. In cases in which there is disagreement on treatment between a physician and an infant's family, and the family wishes to continue life-sustaining treatment, the ICRC should counsel that the family's wishes be carried out, for as long as the family wishes, unless such treatment is medically contraindicated. When there is physician/family disagreement and the family refuses consent to life-sustaining treatment, and the ICRC, after due deliberation, in accordance with the policies, principles and procedures set forth above, agrees with the family, the ICRC should counsel that the treatment (other than appropriate nutrition, hydration, and medication) be withheld. When there is physician/family disagreement and the family refuses consent, but the ICRC disagrees with the family, the ICRC should counsel that the hospital board or appropriate official immediately refer the matter to an appropriate court or child protective services agency in accordance with applicable reporting requirements and related procedures, and that every effort be made to continue treatment, preserve the status quo, and prevent worsening of the infant's condition until such time as the court or agency renders a decision or takes other appropriate action. The ICRC should also follow this procedure in cases in which the family and physician agree that life-sustaining treatment should be withheld or withdrawn, but the ICRC disagrees.

B. *Retrospective Record Review.* For the purpose of monitoring the effectiveness of policies and procedures of the hospital and ICRC, the Department recommends that the ICRC, at its regularly-scheduled meeting, review all records involving withholding or termination of medical or surgical treatment to infants consistent with hospital policies developed by the ICRC, unless the case was previously before the ICRC for emergency review. If the ICRC finds that a deviation was made from the institutional policies in a given case, it should conduct a review and report the findings to appropriate hospital personnel for appropriate action. If the ICRC finds that revisions to institutional policies are necessary or appropriate, it should develop appropriate recommendations.

Approved:

Dated: April 1, 1985.

C. Everett Koop,

Surgeon General, U.S. Public Health Service.

Dated: March 29, 1985.

Dorcas R. Hardy,

Assistant Secretary for Human Development Services.

Dated: April 5, 1985.

Margaret M. Heckler,

Secretary.

Appendix

Analysis of Model Guidelines for Health Care Providers to Establish Infant Care Review Committees and Comments Submitted Regarding Interim Model Guidelines.

1. *Introduction*

Section I of the model guidelines includes introductory information to lay the foundation for the Department's recommendation that hospitals establish ICRC's. The Department believes the factors identified are particularly pertinent with respect to hospitals with tertiary level neonatal care units, and thus especially recommends ICRC's for such hospitals.

A number of comments submitted in connection with the interim model guidelines expressed concern that although the interim guidelines were identified as advisory, the format, structure and wording could give the impression that they were mandatory or that there were some legal, regulatory or administrative enducements associated with them. Some commenters expressed the view that the interim guidelines were too inflexible to accommodate diversity among hospitals, and suggested that a different type of model, such as one that identified significant concepts and suggested alternative approaches, would be better. Some commenters who indicated misgivings about the potential effectiveness of ICRC's suggested the Department soften the degree to which it recommends ICRC's.

In response to these concerns, the Department has revised some of the introductory material to clarify that the guidelines are *purely* advisory, that establishment of an ICRC and/or adoption of this model does not relieve any legal responsibilities of the hospital (including responsibilities relating to State child protective services activities), and that every hospital is completely free to adopt, adapt, or ignore the model. In short, these model guidelines are accompanied by neither carrots nor sticks.

The comments, however, have not shaken the Department's belief that ICRC's can be very valuable in advancing the objective of assuring the provision of appropriate medical care to disabled infants with life-threatening conditions, and that the Department's legislative charge is to develop a model that includes those principles and procedures the Department believes are important for ICRC's to realize their potential efficacy. The Department recognizes that realization of this potential will require not only dedication to the concept of ICRC's, but also persistence in evaluating and sharing information about experience with ICRC's, including those that are based on different models, to facilitate informed judgments about possible refinements and improvements.

With all of these considerations in mind, the introductory information continues to recommend strongly ICRC's, especially for hospitals with tertiary level neonatal care units, and to urge careful consideration of all elements of this model.

2. Establishment and Purpose

This section of the model guidelines lists the purposes and functions of the ICRC in the terms set forth in the Act. It is not materially changed from the provision included in the interim guidelines. Some commenters suggested a different name for the committee, such as "Infant Bioethics Committee" or some other term that emphasized the committee's function of considering questions of medical ethics. The Department has not changed the title of the committee because nothing in the authorizing statute corroborates the notion that the focus of the committee should be "medical ethics," at least to the extent that term connotes considerations different than those involved in evaluating medical treatment possibilities that "will be most likely to be effective in ameliorating or correcting" all life-threatening conditions. Thus, the Department continues to believe the title "Infant Care Review Committee" best characterizes the purposes and functions of the committee.

3. Memberships of the ICRC

Section III–A of the model guidelines recommends the membership of the ICRC. The Department received numerous comments regarding this section of the interim guidelines. Some commenters suggested that no particular membership should be specified to permit more flexibility, such as an option to limit membership to the hospital's medical staff. Some commenters suggested that more specific qualifications and credentials should be required for membership, such as requiring that the nurse be a registered professional nurse, that the physician be a neonatologist, that the social worker have certain credentials, that the representative of a disability group have certain training or professional standing, and the like. Some commenters urged that members from other disciplines should be represented, such as a special education teacher, an ethicist, a family physician, and the like. Some commenters proposed that the ICRC should have a more formal mechanism for advocacy for disabled infants, such as the inclusion of a trained child advocate appointed by an independent entity, the inclusion of a permanent "special advocate," or the like. Some commenters recommended that the ICRC should have a higher number or percentage of physicians and other medical professionals.

In response to these comments, the Department has made several changes to the model from what appeared in the interim guidelines. First, the model now identifies the key concept that should be the basis for decisions on membership: That the ICRC should consist of individuals from varied disciplines and perspectives. Second, the model now identifies a recommended core membership that is designed to implement this multi-disciplinary approach, and provides further suggestions for supplementing the core membership on a permanent or other formal or informal basis. Third, a representative of the legal profession has been dropped from the recommended core membership and included in the list of individuals to be considered for supplementation of the core membership because legal counsel for the ICRC is elsewhere (in section III–B–1) provided.

The Department believes these revisions strike an appropriate and workable balance between the need for a multi-disciplinary approach and the unworkability of forming a committee with a representative of every discipline, perspective or group that might have a more refined or more general or more expert or different point of view. The use of one or more of the suggested mechanisms for supplementing the disciplines and perspectives represented by the core membership reinforces the prime concept of a multi-disciplinary approach without making the ICRC unworkable.

The Department rejects the argument that no committee membership should be recommended because the Department believes adoption of the multi-disciplinary approach is vital to the effectiveness of the ICRC. However, although the Department recommends the selection of highly qualified individuals, the Department believes it unnecessary to specify certain educational or other credentials for members.

In addition, the Department has not adopted the various suggestions for formal advocacy for disabled infants. In judicial proceedings involving a neglected child, it is vital that the child have a skilled, independent advocate. For this reason, section 4(b)(2)(G) of the Federal Child Abuse Prevention and Treatment Act requires that a guardian ad litem be appointed to represent the child in all such proceedings. But the Department believes the functions of the ICRC are much different from those of a court. A court makes a binding decision on the rights and responsibilities of the parties before it. In contrast, the function of the ICRC is, as set forth in the statutory directive for HHS to issue these guidelines, to educate hospital personnel and families, to recommend institutional policies, and to "offer counsel and review" in specific cases. Therefore, the Department believes it is neither necessary nor appropriate to replicate a guardian ad litem function on the ICRC.

4. Administration of the ICRC

Section III–B of the guidelines addresses several matters regarding the administration of the ICRC. Paragraph two calls for procedures to ensure that both hospital personnel and patient families are fully informed of the existence and functions of the ICRC and its availability on a 24-hour basis. Some commenters suggested this information also be widely publicized to the public to facilitate requests from persons other than hospital personnel and patient families for review of specific cases. The Department has not adopted this suggestion. Although child protective services agencies permit any person to make reports of suspected child abuse and neglect, including suspected medical neglect involving the withholding of medically indicated treatment from disabled infants with life-threatening conditions, HHS does not view the functions of the ICRC in the same light. The ICRC is not designed to be an arm of the State child protective services system, and thus procedures appropriate for that system are not necessarily appropriate for the ICRC. The purpose of the ICRC is to assist the hospital in assuring the provision of medical care and related service that are consistent with good medical standards and the obligations of the hospital and medical personnel under applicable law. Rather than replicate procedures of the child protective services system, the guidelines, in section V–B, call for the ICRC to develop recommended policies to facilitate effective coordination and cooperation between the hospital and the child protective services system.

Paragraph three calls for the ICRC to inform itself of pertinent legal requirements and procedures, including those relating to child protective services agency activities. In response to comments, a sentence in the interim guidelines that called for the ICRC to consult with the child protective services agency has been deleted from this model. A new provision has been added to section V–B to deal with the issue of the relationship between the ICRC and the State child protective services agency.

Paragraph four relates to maintenance and confidentiality of records. Some commenters suggested a more limited provision concerning the confidentiality of records than the provision in the interim model guideline that records be made available to appropriate government agencies, or upon court order, or as otherwise required by law. Other commenters proposed more detailed record-keeping requirements, such as maintaining taped or detailed written minutes of all meetings, and a provision for regular transmittal of these materials to the State child protective services agency. HHS has made no material change in this provision. Matters regarding the confidentiality of medical records and the availability of those records to courts, administrative agencies, and the like, are already specifically dealt with under the law. The Department does not believe it appropriate to try to establish a new or different set of standards for this purpose. The Department has also not adopted more detailed recordkeeping standards of the ICRC. HHS does not believe the standard procedures applicable to judicial proceedings or certain administrative activities, which may require transcripts or other detailed records, are necesssary or appropriate in relation to the purposes and functions of ICRC's.

Some commenters suggested a provision be added to the guidelines to provide immunity or idemnification for the ICRC and its members against any potential civil liability for actions taken by the ICRC. The Department has no power to grant immunity, nor does HHS have sufficient familiarity with the pertinent provisions of State law that might have a bearing on the issue to recommend that hospitals and ICRC's take any particular action on this question. Hospitals and ICRC's that believe it appropriate to explore this question further should consult with their counsel.

5. Educational Activities

Section IV of the guidelines outlines recommended ICRC activities relating to its function of educating hospital personnel and families of disabled infants with life-threatening conditions. In response to public comments, one change has been made from the interim guidelines, adding that, when appropriate, the ICRC make available to hospital personnel and families information concerning adoption placement counselling and services in the community.

No changes have been made in response to some comments that the educational activities listed exceed the capabilities of ICRC's or would require a full-time staff member, or to other comments that the activities listed are duplicative or other activities already being performed by hospital staff. The Department believes the activities listed are not excessive, and nothing in the model suggests that an ICRC is supposed to isolate itself from the ongoing activities of various units of the hospital that normally engage in social services counselling and assistance, in-house educational activities, the provision of information to patients and their families, and the like.

6. Policy Development

Section V of the model guidelines outlines activities relating to the function of the ICRC to recommend institutional policies and guidelines concerning the withholding of medically indicated treatment from disabled infants with life-threatening conditions. Section V–A sets forth the basic policy that should guide the ICRC.

Some commenters sought clarification of what they viewed as an inconsistency between the reference at some places in the interim guidelines to "developing" policies and guidelines and the reference at other places in the model to "recommending" policies and guidelines. The statutory provision that directed the Secretary to issue these model guidelines refers to this purpose of the ICRC as "recommending institutional policies and guidelines." Nothing in the interim guidelines was intended to deviate from this standard, and several changes have been made in section V to avoid any lack of clarity on this point.

Some comments suggested that the statement of the ICRC's "basic policy," stated in the model as "to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions," was too narrow in that it dealt with only one function of the ICRC, and that it should be made more general. The Department, in making no material change to this statement, is guided by the statutory language, which decribes the "policy" purpose of the committee as "recommending institutional policies and guidelines concerning the withholding of medically indicated treatment (as that term is defined in clause (3) of section 3 of the Act . . .)" from disabled infants with life-threatening conditions. The incorporation of the definition of the term "withholding of medically indicate treatment" contained in section 3 of the Child Abuse Prevention and Treatment Act, as amended by the Child Abuse Amendments of 1984, and the context of the 1984 amendments make clear that policies "regarding" the withholding of medically indicated treatment should be guided by the principle that policies and guidelines should be designed "to prevent" such withholding. Thus, the Department believes that in developing recommended institutional policies and guidelines, the guiding principle should be to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

Paragraph one of section V–A sets forth the statutory definition of "withholding of medically indicated treatment," which, as noted above, is incorporated into the statutory directive that the Secretary issue these model guidelines. Paragraph two sets forth two definitions of terms contained in the basic statutory definition. These two definitions are taken from the Conference Committee Report on the Child Abuse Amendments of 1984.

The interim model guidelines also included provisions relating to definitions of other terms used in the definition of "withholding of medically indicated treatment," provisions that were identical to definitions included in the proposed regulation to implement the Child Abuse Amendments of 1984. In response to comments regarding these provisions in the proposed rule and interim model guidelines, they were not adopted in the final rule, and have similarly not been adopted in these final model guidelines.

The appendix to the final rule, however, includes the Department's interpretative guidelines regarding terms used in the statutory definition. It also includes a detailed discussion of these interpretations, as well as the comments received by the Department. The information contained in the appendix to the final rule may assist the ICRC in understanding dimensions of the definition of "withholding of medically indicated treatment." The Department recommends in paragraph (3) that the ICRC carefully review the appendix to the final rule.

7. Development of Specific Policies and Guidelines

Section V–B of the model guidelines recommends specific activities of the ICRC relating to its function of recommending institutional policies and guidelines. A new paragraph (three) has been added to the material that appeared in the interim model guidelines. Paragraph three is included in response to many comments that urged revisions or clarifications to the model in connection with the issue of the interaction among: (a) The ICRC; (b) the child protective services system; and (c) other individuals within the hospital with responsibilities relating to the child protective services system's activities.

This issue involves several factors. First, under the Child Abuse Amendments of 1984, State child protective services agencies must, as a condition of eligibility for Federal assistance, have in place certain programs and/or procedures "for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions)." Second, these programs and/or procedures must provide for "coordination and consultation with individuals designated by and within" hospitals. Third, they must also provide for "prompt notification" by such individuals of suspected medical neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions. And fourth, other provisions of State law relating to child protective services activities, including reporting obligations of medical personnel and hospitals, investigative authorities, responsibilities and procedures, and the like, are applicable to reports of suspected medical neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions.

The issue, thus, is how the ICRC should relate to these various responsibilities and activities. The model does not provide a specific answer because the procedures implemented in particular hospitals should take into account the pertinent provisions of State law and local agency procedure, which are not necessarily uniform throughout the United States. The model, therefore, calls on the ICRC to look into these matters and to develop, in connection with its other policy development activities, recommended procedures for the hospital to implement in order to facilitate effective coordination with the child protective services system, as well as coordination between the ICRC and other hospital officials in relation to matters of interest to the child protective services agency in connection with the withholding of medically indicated treatment for disabled infants with life-threatening conditions.

It should be noted that the model does not specifically call for the ICRC chairperson or members to be the "designated individuals" for the liaison function with the child protective services agency. Such a designation, however, might best facilitate effective coordination and cooperation with the child protective services agency. On the other hand, some hospitals might prefer to incorporate this into existing coordination mechanisms applicable to the full range of potential child abuse and neglect issues. Therefore, although there are strong reasons for assigning the ICRC chairperson or other member the liaison function, the model does not specifically call for this, but rather recommends that the ICRC itself address this and the related issues.

A number of other comments were received concerning this section of the interim model dealing with development of specific policies and guidelines. Some commenters argued that the activities called for in the interim model guidelines were excessively prescriptive and would lead to unreasonable interference in medical management. The Department intended nothing unusual or overly prescriptive in suggesting that ICRC's develop recommended guidelines for management of particular types of cases and procedures to be followed in recurring circumstances. Some revisions to the language have been adopted to clarify this intent.

Other commenters suggested that the model provide that all specific policies developed by the ICRC for recommended adoption by the hospital be submitted to and approved by the State child protective services agency prior to adoption by the hospital. This suggestion has not been adopted because the Department does not believe the legislative directive to the Secretary to issue these model guidelines can be construed to support a concept that ICRC's are to be directly regulated by child protective services agencies or that they are to be functionaries of the agencies.

8. Prospective Review and Counsel

Section VI–A sets forth recommended procedures for the ICRC to carry out its function of offering prospective review and counsel in cases involving disabled infants with life-threatening conditions. Paragraphs 1 and 2 outline circumstances under which emergency ICRC meetings should be convened. Because of the need for prompt review and counsel, HHS recommends that the ICRC have the capability to convene an emergency meeting within 24 hours (or less if indicated) to consider such cases.

The Department received many comments regarding these paragraphs. Some commenters suggested that in order to avoid unnecessary or excessive meetings, the model not call for emergency meetings when requested by any member of the ICRC or hospital staff or parent or guardian of the infant, and that instead the model should recommend a screening process, such as for the chairperson to decide whether a meeting is appropriate. Other commenters suggested that the model also call for emergency meetings when requested by any interested person on the grounds that some cases that should be reviewed may not come to the attention of the ICRC under the criteria included in the model. HHS has not adopted either suggestion. The Department believes that until each ICRC has gained some experience, it may not adequately be able to judge whether review of certain cases covered by the criteria would actually be unnecessary. Similarly, HHS is unaware at this stage of ICRC experience of the likelihood that cases which should be reviewed would not involve at least one of the seven criteria listed in paragraphs one and two (including when it is "otherwise appropriate"). In the absence of some basis to believe it is necessary, HHS is disinclined to suggest that medical professionals and other ICRC members deal with cases that do not meet any of the criteria upon request of any person with the same urgency and priority as cases that do meet the criteria.

Some commenters suggested that convening meetings on 24-hours notice would be impracticable. Other commenters suggested that the provision in the model (paragraph three) permitting telephone conferences or other methods of review when convening an emergency meeting is impracticable should be deleted because they lack the effectiveness of in-person meetings. HHS has made no material revision to the model in this regard. The Department continues to recommend that ICRC's respond to cases that meet the criteria identified on an urgent (24 hours, or less if necessary) basis, and to recognize that the timing and nature of a case may in certain circumstances make in-person meetings impracticable.

Two additional provisions have been added, in response to comments, to the version of paragraph four that appeared in the interim guidelines. First, consistent with one of the revisions to section III–A (regarding membership of the ICRC), the model suggests that a physician(s) experienced in the evaluation and treatment of the relevant disability(ies) or life-threatening condition(s) be invited, if appropriate, to the emergency meeting. The second revision recommends the ICRC ensure that parents receive appropriate counselling, as well as full information regarding the patient's condition and prognosis.

The Department received many comments regarding the recommendation in paragraph five that the chairperson designate a "special advocate" to ensure that all considerations in favor of additonal treatment are fully considered. Some commenters suggested that the model specify that the "special advocate" must be a trained child advocate independent of the hospital. Other commenters suggested this provision be deleted because it would create an adversarial relationship; it implies other ICRC members are less concerned about the infant's best interests; and it will confuse parents to have someone advocating treatment in every case, even if unjustified.

HHS has made no material change in response to these comments. As noted above in the discussion of section III–A (regarding membership of the ICRC), HHS does not believe the guardian ad litem model is necessary or appropriate for the ICRC. Thus, the model does not recommend formal representation for the infant by a trained advocate. On the other hand, the Department continues to believe that the "special advocate" feature will contribute to a comprehensive evaluation of all options and factors pertinent to the committee's deliberations. It should be noted that the model does not call for the "special advocate" to be a "treatment advocate," if nontreatment is appropriate and permissible under applicable standards. Rather, the special advocate is to ensure that all considerations in favor of additional treatment are fully *evaluated and considered* by the ICRC. This does not require that the special advocate argue, just for the sake of argument, with the judgments of other ICRC members who have fully evaluated and considered all pertinent factors and who believe nontreatment is not inappropriate. It should also be noted that the model guidelines call for the chairperson to make clear to all participants and observers that the designation of a "special advocate" is a standard procedural practice to ensure thorough deliberation, and that it does not imply that any other participant is less concerned about the welfare of the infant.

Paragraph six suggests the kinds of recommendations the ICRC should make in certain circumstances. Some commenters urged revisions to the wording of this paragraph which they thought could be construed as recommending that the ICRC was to act as a decision maker, rather than perform the function of "offering counsel and review," as it is stated in the legislative provision that required the Secretary to issue these model guidelines. No deviation from the statutory concept of "offering counsel and review" was intended, and several revisions to the wording have been made to avoid any misunderstandings in this regard.

A number of commenters recommended revised or additional provisions in the model guidelines relating to the interaction between the ICRC and the child protective services agency. Some commenters suggested that if life-sustaining treatment is not being provided, the ICRC should make a report to the child protective services agency at the conclusion of its meetings, regardless of whether the ICRC believes "medically indicated treatment" is being withheld, in order to permit an independent review by the agency. Some commenters suggested a similar report as soon as the ICRC learns of a case that it intends to review, in order to permit simultaneous review by the agency or monitoring by the agency of the ICRC's deliberations. Some commenters suggested that consideration by the ICRC should permit a delay in reporting to the child protective services agency.

The Department has made no revisions or additions to the model guidelines in response to these comments. As stated above in the discussion of section V–B (regarding the development of specific policies and guidelines), the existence and activities of the ICRC do not amend the responsibilities under State law of medical professionals and the hospital to report to the child protective services agency suspected instances of medical neglect (including the withholding of medically indicated treatment from disabled infants with life-threatening conditions). Nor does the existence of the ICRC reduce or affect the rights of other persons to report suspected cases to the agency. Although the child protective services agency and the ICRC are to be guided by similar principles and standards regarding the best interests of the child, the Department believes they have seperate and distinct functions. The primary function of the ICRC in this context is to offer counsel to the attending physician(s), the hospital and the family to assure that the parents have the benefit of prudent, knowledgeable and professional evaluations, recommendations and services, consistent with appropriate medical standards, to assist them in making sound decisions regarding the welfare of their child. The function of the child protective services agency is to determine those circumstances in which the power of the State must be invoked to protect the infant, and then to take appropriate action to do so. Linkages between child protective services agencies and health care institutions and professionals are already establish in law, and the legislative history of the Child Abuse Amendments of 1984 makes clear these existing mechanisms are to apply in connection with instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions. In view of these factors, the model does not enlarge, contract, or amend the applicable legal standards for reporting to child protective services agencies.

B. Retrospective Record Review

Section VI–B of the model guidelines recommends that the ICRC retrospectively review records in certain categories of cases as a method of monitoring the effectiveness of the policies and procedures of the ICRC and hospital.

In response to some comments that the description of this activity in the interim guidelines gave the impression of an unproductive, after-the-fact fault-finding mission, this section has been revised somewhat to clarify its purpose. Some commenters suggested that the model call for ICRCs to report to the child protective services agency any discovered deviations from hospital policies. Other commenters suggested annual reports to the agency of the results of the ICRC review of all cases, to be followed by compilations by the agency and by HHS for publication. For the reasons set forth in the discussion above regarding section VI–A (concerning prospective counsel and review), the Department has not adopted these suggestions. The reports the ICRC and/or the hospital make to the child protective services agency or any other entity should be those indicated by applicable requirements. With respect to the objective of adding to professional and public knowledge of the potential benefits and difficulties of ICRCs, the Department agrees that activities relating to this objective should be encouraged through the mechanisms of professional and public communications, but believes it is beyond the intended scope of these model guidelines to seek to organize some comprehensive information compilation and distribution system.

[FR Doc. 85–8994 Filed 4–11–85; 10:23 am]

BILLING CODE 4130–01–M

Appendix K

In re Steinhaus

STATE OF MINNESOTA IN COUNTY COURT
COUNTY OF REDWOOD JUVENILE COURT DIVISION

In the Matter of the Welfare of
Lance Tyler Steinhaus, a minor. ORDER

This matter came on before this Court upon the motions of Amy Steinhaus and Dr. David Steinhorn in the courtroom of the Lyon County Courthouse in the City of Marshall, Minnesota on the 14th day of August, 1986, at 9:00 a.m. Mr. David Peterson, 308 North Third Street, Marshall, Minnesota 56258 appeared on behalf of the Redwood County Welfare Department; Ms. Natalie Hauschild, 315 South Washington, Box 377, Redwood Falls, Minnesota 56283 appeared on behalf of petitioner Amy Steinhaus; and Jan D. Halverson, University of Minnesota Hospital and Clinic, Box 708, Harvard Street at East River Road, Minneapolis, Minnesota 55455 appeared on behalf of Dr. David Steinhorn. Present was Mr. Timothy Steinhaus, father of the child, represented by Cecil Naatz, Attorney at Law, Marshall, Minnesota 56258. Present, also, was Mr. Michael Boyle, Attorney at Law, Springfield, Minnesota, representing the child.

The undersigned, upon all the evidence introduced at this hearing and upon all the files and records herein, finds as follows:

FINDINGS OF FACT

1. Lance Tyler Steinhaus was born on March 20, 1986. On or about April 24, 1986 he received serious injuries, including a fractured skull and fractured ribs. The child became comatose on that date and has never regained consciousness. That the child was the subject of a Neglect Petition in Redwood County, Minnesota. That the child was found to be neglected as the result of the actions of the child's father and that custody was placed in the Redwood County Welfare Department.

2. That the child's mother, Amy Steinhaus, after consultation with the child's doctors agreed that the child should not receive antibiotics and that a "Do Not Resuscitate" order should be placed upon his medical chart.

3. That on the Motion of the Redwood County Welfare Department a temporary restraining order was signed on August 1, 1986 which order restrained medical doctors from removing the child from antibiotic treatment.

4. That this matter has come before the Court upon the motion of Amy Steinhaus and Dr. Steinhorn requesting that this Court (1) dissolve the temporary injunction granted on August 1, 1986, and (2) ordering that personal hygiene, nutrition, hydration and suctioning of oral secretions be continued, but that any aggressive medical treatment including antibiotic treatment, resuscitation efforts, surgical interventions and the use of respiratory devices to treat Lance Tyler Steinhaus be proscribed (not required).

5. Doctor David Steinhorn is a Medical Doctor and an instructor of the Department of Pediatrics at the University of Minnesota Hospital. Until shortly before the hearing he was the treating doctor for the child.

6. Dr. Steinhorn testified that the child's current medical condition is one of a "persistent vegetative state". The testimony indicated that the child was not "brain dead" and there was some activity in the brain, although in his opinion this activity pertained to basic primal instincts. He testified that the child is severly impaired that he is unable to handle oral secretions, that he has an ineffective cough and gag so that he cannot clear his airway effectively. The child is fed by a feeding tube directly into his tomach. Dr. Steinhorn defined a persistant vegetative state as having no interaction with his environment and testified that in his opinion the child had no hope of improvement. Dr. Steinhorn testified also that the child is susceptible to life threatening infections and that without antibiotics that he would probably die of infection within a short period of time.

7. That based upon the testimony introduced at trial that the child is a disabled infant with a life threatening condition.

8. Dr. Steinhorn indicated that he has consulted with other doctors including staff prediatric neurologists at the University of Minnesota Hospital and also the Ethics Committee at the University of Minnesota Hospital. That all he has talked to have concurred that the child should have a given "comfort care"

environment without providing any aggressive intervention in the event his heart stopped or he should stop breathing.

9. The doctor testified that in his opinion it would not be in the best interest of the child to try to prolong his life through any type of ventilatory support or the institution of antibiotic therapy.

10. That Dr. Steinhorn did advocate that the child remain on one type of antibiotic which would prevent seizures. That the doctor testified that he would not strongly object to passive administering of antibiotics by means of the stomach tube but that he would object to more intrusive administration of antibiotics by intervenous means.

From the above findings, this Court makes the following:

CONCLUSIONS OF LAW

1. Federal and State law establish a clear and consistent standard for what treatment must be provided disabled infants with life-threatening conditions.

In the wake of considerable public debate over whether and when children with disabilities should receive life-preserving treatment (stimulated by the death of a Bloomington, Indiana child born with Down's Syndrome after surgery, food and water were withheld from him in April, 1982), Congress enacted the Child Abuse Amendments of 1984, Pub. L. No. 98-457, tit. 1, secs. 121-28, 98 Stat. 1749, 1752-55 (codified at 42 U.S.C.A. 5101 to 5103) (Supp. 1986). See generally Bopp & Balch, The Child Abuse Amendments of 1984 and their Implementing Regulations: A Summary, 1 Issues in L. & Med. 91, 95-100 (1985). The law enacted was the product of negotiations among medical, disability rights and pro-life representatives and represented a consensus among a broad range of groups. Groups that supported the final language included, among many others, the American Hospital Association, the National Association of Children's Hospitals and Related Institutions, the American Academy of Pediatrics, the American Nurses Association, the American College of Physicians, the American Association on Mental Deficiency, the Association for Retarded Citizens, U.S., and The Association for Persons with Severe Handicaps. _Id_. at 100; 130 Cong. Rec. S8951, S8952 (daily ed. June 29, 1984).

The legislation applies to all states that receive federal funds under the Child Abuse Prevention and Treatment and Adoption Reform Act. Minnesota receives Child Neglect & Abuse Basic State Grant No. 05 CA 5388/09-2 in the amount of $158,521 for the eighteen months commencing September 30, 1985.

As amended by the 1984 act, 41 U.S.C.A. 5103 (b) (2) (K) (Supp. 1986) provides, "In order for a State to qualify for assistance under this subsection, such State shall...have in place... procedures or program...to provide for...(iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions." In addition, 42 U.S.C.A. 5103 (b)

(2) (C) (1982) requires that "in order for a State to qualify for assistance under this subsection, such State shall...provide that...upon a finding of abuse or neglect, immediate steps shall be taken to protect the health and welfare of the abused or neglected child...".

42 U.S.C.A. 5102 (1982) defines "child abuse and neglect" as including "negligent treatment, or maltreatment of a child..." Under an implementing regulations, 45 C.F.R. 1340.2 (d) (3) (i) (1985) explicitly states, "The term 'medical neglect' means the failure to provide adequate medical care in the context of the definitions of 'child abuse and neglect' in section 3 of the Act [42 U.S.C.A. 5102 (1982)] and 1340.2 (d) of this part. The term 'medical neglect' includes, but is not limited to, the withholding of medically indicated treatment from a disabled infant with a life-threatening condition."

In May, 1985, Minnesota enacted legislation to ensure its compliance with these requirements. As a result, the Juvenile Code now includes in its definition of "neglected child" one "who is medically neglected, which includes the withholding of medically indicated treatment from a disabled infant with a life-threatening condition." Minn. Stat. Ann. 260.015 Subd. 10 (e) (Supp. 1986).

The centerpiece of the Child Abuse Amendments of 1984 is the Act's definition of "withholding of medically indicated treatment." Minn. Stat. Ann. 260.015 (e) (Supp. 1986) also includes a definition of the term that essentially repeats the federal definition.

42 U.S.C.A. 5102 (3) (Supp. 1986) defines "withholding of medically indicated treatment" as:

> the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

See also 45 C.F.R. 1340.15 (2) (1985).

The Federal Department of Health and Human Services, the agency charged with administering the Act, has succinctly summarized the structure of the mandated standard of care as follows:

> [F]irst, all such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication. Second, all such disabled infants must be given medically indicated treatment. Third, there are three exceptions to the requirement that all disabled infants must receive treatment, or, stated in other terms, three circumstances in which treatment is not considered "medically indicated."

Dept. of Health and Human Services, Off. of Human Development Serv., Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. 4816, 48163 (1984).

It is clear that it is this definition of what medical treatment is and is not required, contained in both federal and Minnesota law, that must guide this court in making decisions about Lance Steinhaus.

2. Lance Steinhaus is a "Disabled Infant With Life-Threatening Conditions" Within the Meaning of Federal and Minnesota Law.

The treatment standards of both the federal act (42 U.S.C.A. 5103 (b) (2) (k) (Supp. 1986) and the Minnesota law (Minn. Stat. Ann. 260.015 Subd. 10 (e) (Supp. 1986) apply to "disabled infant(s) with (a) life-threatening condition(s)." Because the Minnesota law is so similar to the federal one, and because it was obviously passed to ensure Minnesota's compliance with the federal law, it would be illogical to give any different interpretation to the meaning of the terms of the Minnesota law than to those of the federal act.

The regulations issued by the federal Department of Health and Human Services to implement the Child Abuse Amendments of 1984 define "infant" as follows:

> The term "infant" means an infant less than one year of of age. The reference to less than one year of age shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age. In addition to their applicability to infants less than one year of age, the standards set forth in paragraph (b) (2) of this section should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been extremely prematurely, or who has a long-term disability.

45 C.F.R. 1340.15 (3) (i) (1985)

Lance is less than one year of age. According to the testimony of Dr. Steinhorn, he is likely to remain in a persistent vegetative state indefinitely. Thus, he has a "long-term disability." It is important to note that the definition makes clear that if particular treatment is required for him now, that treatment should not be discontinued when he reaches one year of age.

Does Lance have a "life-threatening condition"? At the same time it issued the regulations implementing the Child Abuse Amendment of 1984, the Department of Health and Human Services promulgated "interpretative Guidelines Regarding 45 C.F.R. 1340.15 - Services and Treatment for Disabled Infants." Although they were not established "as binding rules of law," the Department explained that "this guidance is intended to assist in interpreting the statutory definition so that it may be rationally and thoughtfully applied in specific contexts in a manner fully consistent with the legislative intent." 45 C.F.R. Part 1340 App. (1985). Guideline 2 discusses the term "life-threatening condition" in a manner that could have been written specifically to address Lance's case:

> It appears to the Department that the applicability of the statutory definition might be uncertain to some people in cases where a condition may not, strictly speaking, by itself be life-threatening, but where the condition significantly increases the risk of the onset of complications that may threaten the life of the infant. If medically indicated treatment is available for such a condition, the failure to provide it may result in the onset of complications that, by the time the condition becomes life-threatening in the strictest sense, will eliminate or reduce the potential

> effectiveness of any treatment. Such a result cannot, in the Department's view, be squared with the Congressional intent.
>
> Thus, the Department interprets the term "life-threatening condition" to include a condition that, in the treating physician's or physicians' reasonable medical judgment, significantly increases the risk of the onset of complications that may threaten the life of the infant.

Id.

Dr. Steinhorn testified that, because of his condition, Lance is susceptible to life-threatening infections. It is for this reason that antifiotics are necessary. Clearly, this susceptibility is a "life-threatening condition" under the Health & Human Services guidelines.

3. That under the law Lance Steinhaus should receive antibiotic treatment as a part of the appropriate nutrition, hydration and medication to which all disabled infants are entitled.

Dr. Steinhorn testified that the child is susceptible to life threatening infections and that without antibiotics it is very likely that he would die from infection. The doctor testified that administering of most antibiotics was relatively easy and could be given the child through his stomach tube. The doctor in fact testified that he had no great objection to administering antibiotic medicine by this method and would recommend that a certain type of antibiotic be given to prevent seizures as being regarded as inhumane while death by infection as being regarded as humane.

This Court finds that the administering of antibiotic treatment is not a heroic measure, but is appropriate medication to which the child is entitled.

4. The Treatment Requirements Applicable to Lance Steinhaus require that He be given Resusitation Unless His Condition Fits one of the Three Exceptions set forth in the Statute. It Is Not Clear whether the Child meets the "Chronically and Irreversibly Comatose Exception of the Statute.

In general the standard of care is subject to three exceptions in which only "appropriate nutrition, hydration and medication" is required.

The first exception is when "the infant is chronically and irreversibly comatose." 42 U.S.C.A. 5102 (3) (B) (Supp. 1986); Minn. Stat. Ann. 260.011 Subd. 10 (e) (1) (Supp. 1986). Dr. Steinhorn testified that Lance is in a "persistent vegetative state." It is not clear that this is the same thing as a coma. A November 1985 medical journal article describes differences:

> *Coma* was defined operationally as a sleeplike, unarousable, unresponsive state in which the partient shows no awareness of self or environment. Such patients (1) do not open their eyes either spontaneously or in a response to any verbal stimulus, (2) utter no comprehensible words, and (3) neither obey commands nor move their extremities appropriately to localize or to resist noxious stimuli.
>
> Patients in the PVS [Persistent Vegetative State], however, are awake without being aware. They open their eyes and look about randomly but do not follow objects or respond to verbal command. The eyes open and blink spontaneously and to menace but are unattentive. Patients may sleep at times. Chewing and bruxism (grinding of teeth) are common, and a grasp reflex is often present.
>
> Hansotia, *Presistent Vegetative State*, 42 Archives of Neurology 1048, 1048 (1985) (footnote omitted).

A standard reference text makes the same distinction:

> *Coma* implies the absence of both arousal and content. In terms of observable behavior, the comatose patient appears to be asleep, but unlike the sleeping, he cannot be aroused from this state...
>
> The patient in the vegetative state appears awake but shows no evidence of content, either confused or appropriate. He often has sleep-wafe cycles but cannot demonstrate an awareness either of himself or his environment.

Levy, *The Comatose Patient*, in I The Clinical Neurosciences 955, 956 (R. Rosenberg ed. 1983) (emphasis in original).

Unless it can be shown that the child is chronically and irreversibly comatose, the exception does not apply. The Court's recollection of the testimony does not support this finding. This matter, however, may be the subject of further testimony and a review of the transcript of the hearing.

5. The Futility Exceptions to the General Requirement of Treatment Do Not Apply to Lance Steinhaus.

The second and third exceptions both relate to treatment which is futile in staving off death for very long. They are:

> (B) the provisions of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival or the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

42 U.S.C.A. 5102 (3) (B) & (C) (Supp. 1986). *See also* 45 C.F.R. 1340.15 (2) (ii) & (iii) (1985); Minn. Stat. Ann. 260.015 Subd. 10 (e) (2) & (3) (Supp. 1986).

Because Dr. Steinhorn gave undisputed testimony that, with treatment, Lance might survive for "decades", none of the language is applicable.

First, the treatment at issue would not "merely prolong dying". HHS Interpretative Guideline No. 5 addresses the meaning of these words:

> The Department interprets the term "merely prolong dying" as referring to situations where the prognosis is for death and, in the treating physican's or physicians' reasonable medical judgment, further or alternative treatment would not alter the prognosis in an extension of time that would not render the treatment futile.
>
> Thus, the Department continues to interpret Congressional intent at not permitting the "merely prolong dying" provision to apply where many years of life will result from the provision of treatment, or where the prognosis is not for death in the near future, but rather the more distant future.

45 C.F.R. Part 1340 App. (1985)

"Decades" are certainly equivalent to "many years of life". Thus, since antibiotics and resusciatation could purchase many years of life, such treatment for Lance would not "merely prolong dying."

HHS Interpretative Guideline Number 6 explicates the meaning of "not be effective in ameliorating or correcting all of the infant's life-threatening conditions."

> Under the definition, if a disabled infant suffers from more than one life-threatening condition and, in the treating physician's or physicians' reasonable medical judgment, there is no effective treatment for one of these conditions that threatens the life of the infant in the near future, then the infant is not covered by the terms of the amendment (except with respect to appropriate nutrition, hydration, and medication) concerning the withholding of medically indicated treatment; but if the nontreatable condition

> will not become life-threatening; but if the nontreatable condition will not become life-threatening until the more distant future, the infant is covered by the terms of the amendment.

There is no indication from the testimony of Dr. Steinhorn that Lance has any life-threatening condition that cannot be treated and will thus inevitably cause his death in the near future even if treatment is provided for other life-threatening conditions. On the contrary, with treatment Lance could live for "decades." Evidently this second clause of the second exception does not apply.

The third clause of the second exception refers to treatment that would "otherwise be futile in terms of the survival of the infant" and the third exception refers to treatment "virtually futile in terms of the survival of the infant." Under HHS Interpretative Guideline No. 8, "The Department interprets the term "virtually futile" to mean that the treatment is highly unlikely to prevent death in the near future."

It is important to recognize that both clauses discuss futility only in the context of "the survival of the infant," not in terms of recovery from the disability. The plain language of the statutes, however, makes clear that the length of life, rather than its quality, is to be the basis for judgments about futility. In addition, the HHS Interpretative Guidelines flatly state, "[T]he definition's focus on the potential effectiveness of treatment in ameliorating or correcting life-threatening conditions makes clear that it does not sanction dicisions based on subjective opinions about the future "quality of life" of a retarded or disabled person. Id.

Since Lance could live for "decades" if treatment is provided, it assuredly cannot be accurately said that the treatment is either "futile" or "virtually futile" in terms of his survival.

The third exception is phrased in the conjunctive; for it to apply, it must be the case both that treatment would be "virtually futile in terms of the survival of the infant" and that "the treatment itself under such circumstances would be inhumane." Since the specifications of the first requirement clearly are not met, treatment could not be withheld even if the second requirement were met.

In Interpretative Guideline No. 9, the Department rejected the view that the statutory language of this exception allows "consideration of the infant's future 'quality of life'."

> The Department strongly believe such an interpretation would be inconsistent with the statute. The statute specifies that the provision applies only where the treatment would be "virtually futile in terms of the survival of the infant," and the "treatment itself under such circumstances would be inhumane." (Emphasis supplied.) The balance is clearly to be between the very slight chance that treatment will allow the infant to survive and the negative factors relating to the process of the treatment. These are the circumstances under which reasonable medical judgment could decide that the treatment itself would be inhumane.

Id. (Emphasis in original.)

In light of the uncontested evidence that Lance could survice for "decades" if provided treatment, it is clear that neither the second nor the third exceptions apply.

NOW THEREFORE, IT IS HEREBY ORDERED,

1. That the Motion of the mother, Amy Steinhaus and Dr. Steinhorn are hereby denied.

2. That this Court's Order of August 1, 1986 is made permanent and it is further ordered that until further order of this Court the minor child Lance Tyler Steinhaus shall be provided with "treatment (including appropriate nutrition, hydration, and medication including antibiotics and resuscitation) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all life-threatening conditions.

Dated: September 11, 1986

George I. Harrelson
Judge of County Court

MEMORANDUM

ISSUE The issue before this Court is whether medical treatment, including antibiotic treatment and resuscitation efforts, should be continued on behalf of Lance Tyler Steinhaus, an infant child who is in a persistant vegetative state.

A DISTINCTION A distinction to be drawn is that the child is not "brian dead." There was testimony that the child's brain shows the existence of recordable activity, although the treating doctor was of the opinion that such activity was minimal and related to primal instincts, such as control of breathing. It is noted that the child is not on any respirator.

BACKGROUND In earlier times organized society reached out to segregate, confine, sterilize, and otherwise discriminate against people with disabilities. It was not until the 1960's and 1970's that a significant disability rights movement got under way in the United States. Suits to secure rights were joined by legislative action that resulted in the enactment of such laws as the Education of the Handicapped Act and the Rehabilitation Act.

UNDERLYING RATIONALE The unspoken but underlying rationale of the motion before this Court is that this infant child has such a profound disability that he exists in a "vegetative state", that he will never be able to live a normal life and that, therefore, he should be allowed to die. This rationale was openly expressed in the Infant Doe case where nutrition and beneficial medical care were withheld from a Down's Syndrome infant on the ground that there was no possibility of a minimally adequate "quality of life". Adopting this rationale or way of thinking would certainly have some benefits. The child's death would allow the mother to proceed with her life. I am informed that the mother is a good mother and a fine person and spends almost every spare minute with the child. The child's death would also put an end to the extensive medical care which must by this time amount to tremendous expense. Arguably, such medical expense could produce more profitable results if applied to the cases with a better prognosis.

There are some problems, however, with this "quality of life" argument. Who decides whether the "quality of life" is adequate? Where is the line drawn?

APPLICABLE LAW The Child Abusement Amendments of 1984 were enacted in the wake of considerable debate over whether children with disabilities should receive life-preserving treatment. The law is now clear that all infant children with life threatening conditions have a right to medically indicated treatment. Lance Steinhaus meets this definition. As the result of this law the child has the right to comfort care consisting of food, water, personal hygiene, and appropriate medication. Appropriate medication in this case indicates antibiotic treatment which will prevent death by infection.

CONCLUSION In enacting the 1984 Amendments, the "quality of life" rationale was rejected. The child clearly has a right to medically indicated treatment including antibiotic treatment which will prevent death by infection. If the child's condition worsens and it is found that he is either chronically and irreversibly comatose, or that he meets one of the other exceptions in the law, then the law would not require heroic measures such as resuscitation. Based upon the evidence introduced, however, the Court can not make this finding at this time.

Dated: September 11, 1986

George T. Harrelson
Judge of County Court

STATE OF MINNESOTA
COUNTY OF REDWOOD

IN COUNTY COURT
FAMILY DIVISION

In the Matter of the Welfare of
Lance Tyler Steinhaus,
a Minor

AMENDED
FINDINGS OF FACT AND
ORDER

- -

The above matter came before this court upon the motions of Amy Steinhaus and Dr. David Steinhorn in the Courtroom of the Redwood County Courthouse in the City of Redwood Falls, Minnesota on the 6th day of October, 1986. Mr. David Peterson, Marshall, Minnesota 56258 appeared on behalf of the Redwood County Welfare Department, Ms. Natalie Hauschild, 315 South Washington, Box 377, Redwood Falls, Minnesota 56283 appeared on behalf of the petitioner Amy Steinhaus; Jan D. Halverson, University of Minnesota Hospital and Clinic, Box 708, Harvard St. at East River Road, Minneapolis, Minnesota 55755 appeared on behalf of Dr. David Steinhorn; Cecil Naatz, Attorney at Law, Marshall, Minnesota appeared on behalf of Timothy Steinhaus; Michael Boyle, Attorney at Law, Springfield, Minnesota appeared on behalf of the guardian ad litem and the child..

The motion brought by Petitioner Amy Steinhaus is for an order amending the Findings of Fact, Conclusions of Law and Order of this Court dated September 11, 1986 so as to find that the minor child, Lance Tyler Steinhaus is "chronically and irreversibly comatose" so as not to require resuscitation or other heroic measures as set forth in that except in 42 U.S.C.A. 5102 (3) (B) (Supp.1986); Minnesota Statutes 260.015 Subd. 10 (e) (1) (Supp. 1986).

The motion by Dr. David Steinhorn is for an order to amend the Findings of Fact, Conclusions of Law and Order of September 11, 1986 finding that a decision by the legal custodian to withold treatment other than appropriate nutrition, hydration or medication would not constitute medical neglect or the witholding of medically indicated treatment as defined in Minn. Stat. ss260.015 Subd. (10) e.

The undersigned, upon all the evidence introduced at this hearing and upon all the records and files herein, find as follows:

FINDINGS OF FACT

1. That on August 14, 1986, Dr. David Steinhorn, one of the treating doctors of Lance Steinhaus, testified that the child was in a "persistant vegetative state" and that he also testified that the child was chronically and irreversibly comatose.

2. That on October 6, 1986, the court received the testimony of Doctor Stephen Smith, a pediatric neurologist. That Dr. Smith testified that he had received the medical record of Lance Steinhaus and that he had examined the child on October 1, 2, 4 and 5, 1986. That the Doctor testified that he had received a CAT scan of Lance Steinhaus taken May 20, 1986 and a MR (Magnetic Resonance) Scan taken September 26, 1986.

3. The Court was presented the CAT Scan of Lance Steinhaus' brain which was contrasted with a CAT Scan of a normal brain. That likewise an MR Scan of Lance Steinhaus' brain was contracted to a MR Scan of a normal brain. That Doctor Smith testified that based upon his examination and an examination of the CAT Scan and MR Scan that both of the hemispheres of the child's brain have been "virtually destroyed". He testified that the normal architecture of the brain is missing and that the major areas of the brain have been replaced by fluid.

4. The doctor testified that only area of the brain not completely destroyed is the brainstem. That the brain stem which controls very basic life control systems such as respiration and temperature shows considerable damage.

5. That the doctor testified that based upon his examination and tests that it is his opinion that while the child has some of the criteria of a "persistent vegetative state" that the child does not have the normal "sleep-wake patterns of that state. The doctor testified that the child in his opinion was chronically and irreversibly comatose. The Doctor further testified that in his opinion there are no foreseeable advances in medical science which could hope to improve the child's condition.

6. That it was the opinion of Dr. Smith at appropriate medical practice would dictate that the child be given nutrition, warmth, cleanliness and medication such antibiotics to treat infection. The doctor testified that approprite medical practice would not require resuscitation or intubation or any heroic efforts for the child.

From the above findings the Court makes the following:

CONCLUSIONS OF LAW

1. That the minor child, Lance Tyler Steinhaus is chronically and irreversibly comatose.

2. That State and Federal law require that the child received "comfort care" consisting of appropriate nutrition, hydration, warmth and medication.

3. That Federal Law, 42 U.S.C.A. 5102 (3) (Supp. 1986) and Minnesota State Law, Minn. State ss 260.015, Subd. 10 (e) under the circumstances of this case do not require treatment other than appropriate nutrition, hydration, warmth and medication.

4. That a decision by the legal custodian of the child to withold treatment other than appropriate nutrition, hydration or medication would not constitute medical neglect or the witholdings of medically indicated treatment as defined Minn. Stat. ss260.015 Subd. 10 (e).

NOW THEREFORE, IT IS HEREBY ORDERED:

1. That the motion of petitioner, Amy Steinhaus is hereby granted.

2. That the motion of petitioner Dr. David Steinhorn is hereby granted.

Dated: October 13, 1986

George I. Harrelson

George I. Harrelson
Judge of County Court

COURT AD[illegible]
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10-13-86